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Influence of family dynamics on mental health and quality of care of family caregivers of individuals with dementia in Latin America

Ivan Panyavin

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Influence of family dynamics on mental health and quality of care of family caregivers of individuals with dementia in Latin America

Doctoral thesis presented by Ivan Panyavin

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Thesis directed by Juan Carlos Arango Lasprilla, Ph.D. and Javier Peña Lasa, Ph.D.

Doctoral candidate | Director | Director

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To Ana, Alexandra, and Maria.

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Table of Contents

List of Tables

List of Figures

We don't see things as they are. We see them as we are.

The Talmud.

Abstract

The present study applied the Stress Process Model in conjunction with concepts derived from structural family theory to create and test a multidimensional model of dementia caregiver family dynamics and mental health functioning, as well as their interplay which ultimately impacts quality of care provision in a convenience sample of 130 family caregivers from Latin America. The obtained results revealed that caregiver family dynamics and mental health are positively related, with a large effect size. Regression analyses indicated that family dynamics variables of cohesion, general functioning, and empathy were significant predictors of caregiver depression, anxiety, and satisfaction with life, respectively; low care recipient cognitive functioning was found to be the only predictor of greater caregiver burden, which was not independently associated with family functioning variables. Hierarchical regression analyses suggested that higher quality of informal care was related to greater levels of empathy and reduced levels of overall dysfunction in caregivers' families. Evaluation of the theory-driven model confirmed a significant interrelationship between lower patient cognitive status and higher subjective burden, which in turn negatively impacted on caregiver mental health and family dynamics. Healthy family functioning was found to be significantly and positively associated with greater quality of care provision directly, as well as indirectly via mental health. Dementia caregiver interventions in Latin America would likely benefit from addressing difficulties experienced when providing care to a patient with greater cognitive decline. Additionally, interventions may be more effective if they incorporate programming or techniques to improve family dynamics, particularly family empathy and general functioning, which were found to impact both caregiver mental health and quality of care provision.

1 Introduction

Dementia is a progressive disorder that causes irreversible changes in the brain, resulting in memory impairments, confusion, difficulties with problem-solving, as well as mood and personality changes (American Psychiatric Association, 2013). It can be caused by a number of conditions, such as cerebrovascular disease, traumatic brain injury, prion disease, human immunodeficiency virus infection, and other medical conditions, or through multiple causation (Harvey, Skelton-Robinson, & Rossor, 2003; Hugo & Ganguli, 2014). However, it is most frequently caused by Alzheimer's disease (AD), which is estimated to be responsible for up to 80% of all dementia cases (Alzheimer's Association, 2013; Mesulam, 2000).

1.1 Epidemiology of AD

Prevalence of AD increases exponentially with increasing age, and doubles every 5 years after age 65 years (Jorm & Jolley, 1998). Among individuals aged 70-75 years about 2-3% are affected, while among those older than 85 years the proportion reaches 20-25% (Ferri et al., 2005). Higher prevalence is generally noted among women than men, primarily because women live longer than men. It is estimated that there are currently 35.6 million people with dementia worldwide (Prince et al., 2013). This figure is likely to double every 20 years and reach 115.4 million by 2050 (Prince et al., 2013), with more than 60% of individuals affected by the disorder living in developing countries (Thies, Bleiler, & Alzheimer's Association, 2013).

The guidelines recently released by the World Health Organization urge governments around the globe to consider dementia as a public health priority, and call for increasing resources to address its spread, especially in low- and middle-income countries, many of which are located in Latin America (World Health Organization, 2012). In these countries dementia has been identified as the single most important contributor to disability in the elderly, and the lack of resources for its diagnosis and treatment there is particularly pronounced (Sousa et al., 2009).

Latin America has experienced a significant increase in life expectancy over the past 60 years (from 51.8 to 74.5 years) with a corresponding increase in the proportion of the elderly population (United Nations, 2008). Consequently, prevalence of dementia in Latin America is the highest in the world (at 8.5% in individuals over 60 years, vs. 6.9% in Western Europe, 6,4% in the United States, or 4.2% in Eastern Asia) (Nitrini et al., 2009; Prince et al., 2013). Such a high rate of dementia has also been attributed to other contributing factors, such as cardiovascular risk factors (e.g., obesity, metabolic syndrome, etc.), higher rates of illiteracy and poverty, lower levels of education and cognitive reserve among the elderly in the region, which may cause earlier appearance of clinical signs of dementia in the Latino elderly (Boissonnet et al., 2011; Nitrini et al., 2009; Subramanian, Perkins, Özaltin, & Smith, 2011). It is estimated that across Latin America by 2020 there will be 4.1 million individuals over 60 years old who are affected by dementia, and this number will increase to 9.1 million by 2040 (Rizzi, Rosett, & Roriz-Cruz, 2014).

With such a staggering number of individuals affected by dementia across various global regions and the entire world, its economic toll worldwide is estimated at $604 billion in 2010 (Wimo, Jönsson, Bond, Prince, & Winblad, 2013). Furthermore, dementia is

projected to become a major public health problem in the coming decades (Trojanowski et al., 2012). In many places around the world it is already a leading cause of hospital and skilled nursing facility admissions, as well as death (Hugo & Ganguli, 2014).

1.2 Neurobiology of AD

First identified by Alois Alzheimer in 1901 (Alzheimer, 1907), the disease which now bears his name is characterized by prominent memory impairment and increasing global deterioration of intellectual functioning and personality, which are caused by progressive degenerative neuronal changes and neuronal loss within the cerebral hemispheres. Definitive diagnosis of Alzheimer's disease can only be made via biopsy or autopsy (Khachaturian, 1985). While its causes are still not well understood (Burns & Iliffe, 2009), postmortem studies demonstrated accumulations of amyloid plaques and neurofibrillary tangles in the neuronal tissue of individuals affected by AD (Zubenko, 1997).

Presence of plaque deposits in grey matter was initially described in the late 19th century (Buda, Arsene, Ceausu, Dermengiu, & Curca, 2009), and refers to extracellular byproducts of neuronal degeneration. These plaques are formed in the synapse of neurons by improper clipping of the amyloid precursor protein (APP), which results in the production and accumulation of an undesirable fragment, beta-amyloid (β-amyloid) (Mesulam, 2000; Suh & Checler, 2002). When these fragments form into larger plaques, they have the effect of preventing neurons from communicating with one another (Andreasen, 2004; Suh & Checler, 2002).

Discovered more recently, tau-proteins are implicated in the formation of another pathophysiological hallmark of AD, neurofibrillary tangles (Weingarten, Lockwood, Hwo, & Kirschner, 1975). These proteins help maintain the molecular structure (microtubule) which is responsible for transporting substances from the nerve cell body to the axon. In AD, however, tau protein is altered, and results in twisting of microtubules, which ultimately aggregate into tangles located inside cell bodies (Mudher & Lovestone, 2002). As with amyloid plaque formation, this process disrupts biochemical communication between neurons, eventually leading to cell death (Chun & Johnson, 2007). As the disease progresses, these processes take place throughout neocortex and the limbic system, but initially affect the hippocampus and other structures of the temporal lobe (Boller & Duykaerts, 2003; Mesulam, 2000), which are crucial for cognitive functions such as memory and learning (Byrne, LaBar, LeDoux, Schafe, & Thompson, 2014; Squire, 1992). Consequently, subjective and objective complaints in these areas of cognitive functioning are among the first reported problems by AD patients and those close to them (Hodges & Patterson, 1995). The progression of the disease is gradual, and severity of symptoms at different stages varies from individual to individual (Alzheimer's Association, 2013).

1.3 AD Diagnostic Criteria

Although the progression of AD is accompanied by identifiable structural changes in the cerebral cortex, at the present time its definitive diagnosis is not possible except via direct examination of the brain itself upon autopsy or via biopsy. Instead, clinical diagnosis is based upon documented history of memory impairment and symptom progression, through cognitive testing, detailed social and personal history, and ruling out other causes

of symptomatology through physical, neurological, and laboratory examinations. Rapid scientific progress in the study of etiology and symptomatology of Alzheimer's disease in recent years is evident in the evolution of its diagnostic criteria.

While a number of diagnostic criteria for AD have been published (e.g., the International Classification of Diseases-10, the International Working Group for New Research Criteria for the Diagnosis of AD Criteria, etc.), the following two sets of criteria are the most frequently used in clinical practice (Tarawneh & Holtzman, 2012). One influential set of diagnostic criteria for AD was established by the National Institute on Neurological and Communicative Disorders and Stroke and the Alzheimer Disease and Related Disorders Association (NINCDS/ ADRDA) workgroup, which was convened in 1984 (McKhann et al., 1984). These criteria are used in research as well as clinical settings, and classify AD into "possible", "probable", or "definite". Diagnostic impression of *possible* AD is made when there is presence of a dementia syndrome without known etiology, but with an atypical onset, presentation, or progression, and no comorbid diseases capable of producing dementia. Criteria for the diagnosis of *definite* AD includes the requisite step of meeting the criteria for probable AD, with subsequent histopathologic evidence obtained from a biopsy or autopsy. Therefore, the prerequisite criteria for *probable* AD include: symptom onset between ages 40 and 90 (most often after age 65), absence of disturbance of consciousness and any systemic disorders or brain diseases which could account for dementing symptoms, dementia established via clinical examination and documented by a valid examination (e.g., Mini-Mental Status Examination, Blessed Dementia Scale, or similar) and confirmed by neuropsychological testing, progressive worsening of memory and other cognitive functions, and deficits in two or more areas of

cognition (e.g., language, perception, or motor skills). Such diagnostic impression of probable AD can be supported by alterations in patterns of behavior and presence of impairment in activities of daily living, normal results on certain laboratory and diagnostic tests (e.g., lumbar puncture, electroencephalogram), and evidence of structural brain changes consistent with cerebral atrophy documented by serial observation via structural neuroimaging (McKhann et al., 1984).

These criteria have recently been revised by the National Institutes on Aging-Alzheimer's Association (NIA-AA) workgroup to incorporate modern laboratory, clinical, and imaging assessments of various biomarkers of AD (McKhann et al., 2011). AD biomarkers refer to anatomical and biochemical variables which measure specific pathologic disease-related features, for example amyloid levels and deposition measured via cerebrospinal fluid or positron emission tomography, as well as neurodegeneration detected with structural MRI. Currently, however, the biomarker testing for AD is more frequently performed in research studies and clinical trials (Wu, Rosa-Neto, & Gauthier, 2011), and is not routinely recommended in clinical settings recommended (Knopman et al., 2001; Menéndez-González, 2014).

The second extensively used set of diagnostic criteria for AD is published in the Diagnostic and Statistical Manual of Mental Disorders (DSM). Until recently its fourth edition (American Psychiatric Association, 2000) was widely employed, but it has been updated and replaced in 2013 when the DSM-5 was published. This latest issue created a new term for dementia, referring to it as major neurocognitive disorder (NCD). NCD is diagnosed as "Due to Alzheimer's Disease" when a person experiences significant cognitive decline in one or more of six cognitive domains (learning and memory, language,

executive function, complex attention, perceptual-motor, or social cognition), with insidious onset, gradual progression of decline, and absence of evidence of other etiology, such as cerebrovascular disease (American Psychiatric Association, 2013). The decline must be reported by the individual or their informants (e.g., family members, caregivers, etc.), confirmed by standardized neuropsychiatric testing, and cannot be better accounted for by another mental disorder or delirium. These criteria vary from their earlier iteration by inclusion of social cognition as a possibly affected domain of cognition.

Similar to the NIA-AA criteria, the DSM-5 also categorizes NCD due to AD into "probable" and "possible". Probable NCD due to AD is diagnosed when a person presents with evidence of progressive decline (i.e., without extended plateaus) in memory and learning and in at least one of the other five domains of cognition, as confirmed by repeated neuropsychological testing, or when a specific genetic mutation associated with AD is identified in the individual or an affected family member, via family history or genetic testing (American Psychiatric Association, 2013). Unlike the criteria published by McKhann and colleagues (2011), however, the DSM-5 suggests that the available evidence is still not so conclusive as to warrant the inclusion of biomarkers as part of diagnostic criteria for AD. In summary, for the diagnosis of Alzheimer's disease dementia, both the DSM-5 and the NIA-AA criteria require the presence of dementia, decline in memory/ learning and at least one more cognitive area, insidious onset and gradually progressive decline, and ruling out of other causes for the impairment (American Psychiatric Association, 2013; McKhann et al., 2011).

The overarching theme in the diagnosis of AD is the presence of cognitive or behavioral symptoms which on the one hand represent a decline from a previous level of

functioning, and on the other interfere with a person's ability to function during their daily activities, for example at work or social events. Since some degree of cognitive slowing is typical of normal aging (Hedden & Gabrieli, 2004; Salthouse, 1991), the clinician's challenge lies in identifying those changes in cognition which are the most clinically significant. The role of neuropsychological testing in this process is of utmost importance, and requires a reliable demonstration of observable, measurable deficits in at least two cognitive domains.

Establishing the presence of deficits in cognitive functioning in neuropsychology is accomplished by comparing a person's performance on established tests with that of a normative sample of healthy, non-demented individuals who are equivalent in age, education, and gender (Lezak, 2004). Interindividual comparison of psychometric performance does not necessarily establish whether the performance which may fall in an impaired range represents a decline from the previously held level of cognitive performance for the person. That is why repeated testing of a person with possible or probable AD is extremely important in order to establish the basis for intraindividual comparison of performance on cognitive measures and increase the likelihood of accurate diagnosis (Budson & Solomon, 2015). While many test measures have been developed and validated for the purpose of assessing various cognitive domains possibly affected by dementia, they still leave much room for improvement. On the one hand, it has been suggested that normative, healthy/ non-demented samples may actually include persons with presymptomatic AD, which may lead to substantial underestimation of normal performance and overestimation of the effect of age in the elderly (Sliwinski, Lipton, Buschke, & Stewart, 1996). On the other, possible ethnic and cultural biases in the testing instruments

may also negatively impact the ability of neurocognitive testing to correctly detect and diagnose AD, particularly at its early stages (Manly et al., 1998). This is especially evident in the developing countries, such as those in Latin America, where normative data on neuropsychological measures has not been available until quite recently, forcing clinicians to use the norms developed in other countries (Arango-Lasprilla et al., 2015). Consequently, there is a need for further culture-specific scientific study of various processes involved in AD, from its etiology and epidemiology, to how it affects the patients and their immediate surroundings, including their family and loved ones—who tend to assume major responsibility for their care (Brodaty & Donkin, 2009).

1.4 Dementia Impact on Informal Caregivers

The destructive effects of AD extend beyond imposing significant economic burdens on public health systems and devastating effects on those affected by the illness. Due to its progressive and debilitating course, dementia affects the individual as well as their families (Brodaty & Donkin, 2009). As a result of the disease's effect on the behavioral, cognitive, and emotional functioning, individuals with dementia require increasing amounts of assistance with activities of daily living, including self-care, dressing, meal preparation, and finance management (Thies et al., 2013). Most assistance is provided by informal caregivers (i.e., family and friends) (Schulz & Martire, 2004), with the largest proportion consisting of female spouses, children, and children-in-law (Prince & 10/66 Dementia Research Group, 2004).

Negative effects of providing informal care to a person with dementia (PwD) are well documented. These effects include an undesirable impact on caregivers' physical functioning, manifested by sleep disturbances, hypertension, compromised immune system functioning, and even overall increased mortality rates (Golodetz, Evans, Heinritz, & Gibson Jr, 1969; Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991; S. Lee, Colditz, Berkman, & Kawachi, 2003; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Shaw et al., 1999). Additionally, providing informal care results in diminished social support (e.g., fewer socialization opportunities due to activity restrictions and reduced personal time) (Morris, Morris, & Britton, 1988; Stoltz, Udén, & Willman, 2004), and creates profound psychological and emotional health consequences, such as increased rates of depression (George & Gwyther, 1986), anxiety (Mahoney, Regan, Katona, & Livingston, 2005), and burden (Black & Almeida, 2004; George & Gwyther, 1986; Mahoney et al., 2005; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007).

In the context of providing care to a PwD, the construct of burden has emerged as a particularly important and salient one. Published data suggest that there is some conceptual overlap between measures of depression and burden, and they are both related to similar variables (Miller, Rosenheck, & Schneider, 2012; Möller-Leimkühler & Wiesheu, 2012; Orgeta & Sterzo, 2013). On the other hand, the magnitude of their respective associations with these variables differs (Lim, Ahn, & Ahn, 2015; Stewart et al., 2016), and correlations between depression and burden indicate that some of the variance between them is not shared (Black & Almeida, 2004; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). As measurable constructs of mental health functioning, depression and burden are overlapping, but not identical.

Little published research exists on the topic of caregiver burden, also referred to in the literature as role engulfment (Skaff & Pearlin, 1992), spousal burnout (Ekberg, Griffith, & Foxall, 1986), and caretaker role fatigue (Goldstein, Regnery, & Wellin, 1981), prior to the 1960s. In one of the earliest published studies, Townsend (1957) interviewed 192 men and women in London about their experiences of caring for an elderly person in their home. Having defined burden as excessive physical or mental demands imposed on the family structure by the task of providing care, it was discovered that nearly one in five caregivers reported having experienced moderate or severe strain within their family unit due to limited social and physical resources available for care provision (Townsend, 1957).

Subsequent early seminal studies on burden were also conducted in England. In the context of providing informal care to a family member with mental illness, Grad and Sainsbury (1963) defined burden as any cost to the family. A few years later, the construct of burden was modified and expanded by Hoenig and Hamilton, who argued that "burden" may mean different things to the patient and the family, particularly if they take to providing care from a sense of social obligation or out of love, and thus may not perceive it as a negative event (Hoenig & Hamilton, 1966). Further, they suggested a distinction between objective and subjective types of burden. In the context of their research of the impact of caring for a loved one with schizophrenia on the family unit, objective burden was defined as measurable adverse effects of care provision on the household (e.g., financial loss, time spent on providing care, effects on health, etc.), as well as disturbing abnormal behavior exhibited by the patient (Hoenig & Hamilton, 1966). Subjective burden, on the other hand, was construed as the family members' own feelings and perceptions of the experience of providing care, and to what extent they thought they were burdened. It

was found that while sociodemographic variables of age, sex, and social class had little effect, duration of illness was related to increase in both types of burden; in terms of subjective burden, 51% of participants indicated having experienced "some burden", and 9% "severe burden" (Hoenig & Hamilton, 1966). Another influential study found that caregivers' subjective perception of high burden was not related to dementia patients' behavioral problems, but was instead predicted by low frequency of family visits, highlighting the importance of social and family support for optimal caregiver functioning (Zarit, Reever, & Bach-Peterson, 1980). This study also produced one of the most widely used measures of caregiver burden, the Zarit Burden Interview.

Current research literature conceptualizes caregiver burden as a multidimensional response to perceived stress and the negative appraisal as a consequence of providing care to an ill individual (Kim, Chang, Rose, & Kim, 2012). Recent studies have identified various potential sources of burden for dementia caregivers. Among patient characteristics, higher frequency of behavioral and psychiatric symptoms of dementia, lower patient cognitive functioning, and higher dependence on assistance with activities of daily living have been identified as predictors of higher caregiver burden (Arango-Lasprilla, Moreno, Rogers, & Francis, 2009; Cheng, Lam, Kwok, Ng, & Fung, 2013; Kang, Lee, Lee, & Kim, 2007). Caregiver characteristics, such as female gender, lower income and level of education (Papastavrou et al., 2007), neurotic personality traits (Choi & Kim, 2008), emotional-focused coping style (Kim et al., 2012), lower relationship satisfaction with the patient and family (Papastavrou et al., 2011) also have been found to significantly predict higher burden. Factors related to the caregiving situation which are predictive of greater caregiver burden are higher number of hours caregiving per week (Bruvik, Ulstein,

Ranhoff, & Engedal, 2013), longer total duration (months or years) of care provision (Baker, Robertson, & Connelly, 2010), and fewer sources of social support and worse family functioning (Shurgot & Knight, 2005). While, as a group, caregivers show negative effects of providing care, there are also important individual differences in their reactions. Some caregivers may experience low morale, severe depression, and/ or physical sequelae, while others do not succumb to such negative consequences despite facing severe stress (Zarit, Johansson, & Jarrott, 1998).

1.5 Theoretical Models of Caregiver Adjustment

In order to explain apparent interindividual differences in caregiver functioning, various stress process models (Elliot & Eisdorfer, 1982; W. Haley, Levine, Brown, & Bartolucci, 1987; Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990) have been developed and employed to attempt provide a coherent theoretical underpinning for identifying caregiver risk and protective factors, as well as for designing effective psychosocial interventions.

One of the earliest, and most basic, of such theories conceptualized the effect of the caregiving experience in terms of interactions between the environment and the individual (Elliot & Eisdorfer, 1982). Within this model, a potential activator or stressor (X), an individual's reaction (Y) to the stressor, and the consequences (Z) to the reactions interact via mediating variables to produce individual variations in outcomes as a function of exposure to stressful events and situations (Figure 1).

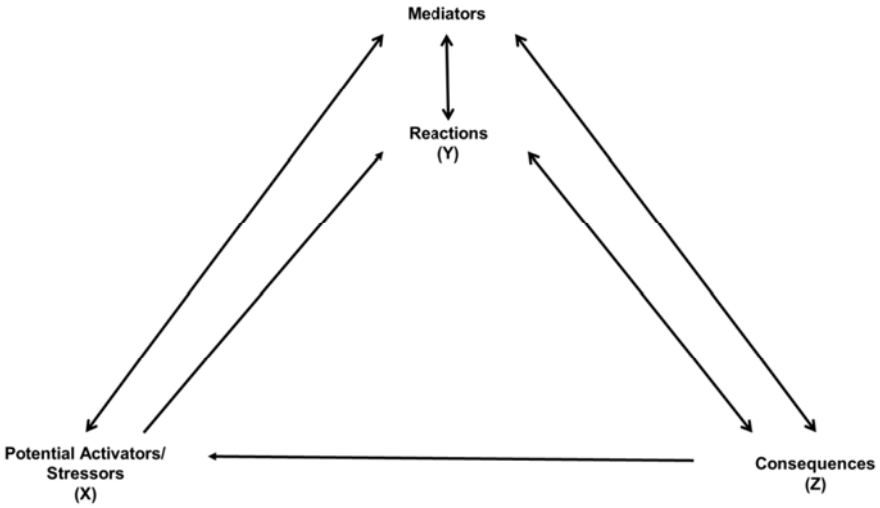

Figure 1. Stress and coping model.

Another important theoretical approach was developed around the same time by Lazarus and Folkman (1984). Conceptually comparable, their model similarly posited an important relationship between caregiving stressors, such as care recipient's functional or cognitive status, and outcomes (e.g., impact on physical or mental health). Moreover, the authors stressed the importance of adaptive and realistic perception of reality for appropriate adjustment and functioning in everyday life. In this way, the degree and amount of negative caregiver outcomes varies as a function of mediating variables (e.g., coping skills, social support) as well as how caregivers appraise the stressors (Lazarus & Folkman, 1984).

Both of these theoretical approaches owe their origins to research conducted by Hans Selye (1956), who developed the concept of the general adaptation syndrome. In his pioneering work Selye was one of the first to make a connection between exposure to stress

(a term which he introduced in biological and psychological research) and resultant physiological changes, such as disease, in the body (Selye, 1956; Viner, 1999). But, given that providing family-based care to a seriously ill person is a multidimensional endeavor with a potentially large and varying number of stressors, its underlying processes and outcomes could not be adequately captured in rudimentary, linear terms.

Drawing on the work of Lazarus and Folkman (1984), Pearlin developed an influential conceptual model which is able to more accurately account for the complexity of stressful experiences and their sequelae (Pearlin, 1989). This work served as the basis for the Stress Process Model (SPM) (Pearlin et al., 1990), which has become one of the most widely employed in research with dementia caregivers to better understand their experience and to develop empirically-derived interventions in order to improve functioning and quality of life. Besides primary stressors and outcomes, the SPM includes contextual factors, appraisals of primary stress, secondary stressors, and various buffers and mediators of stress (Figure 2) to account for multidimensional nature of care provision to a person with dementia.

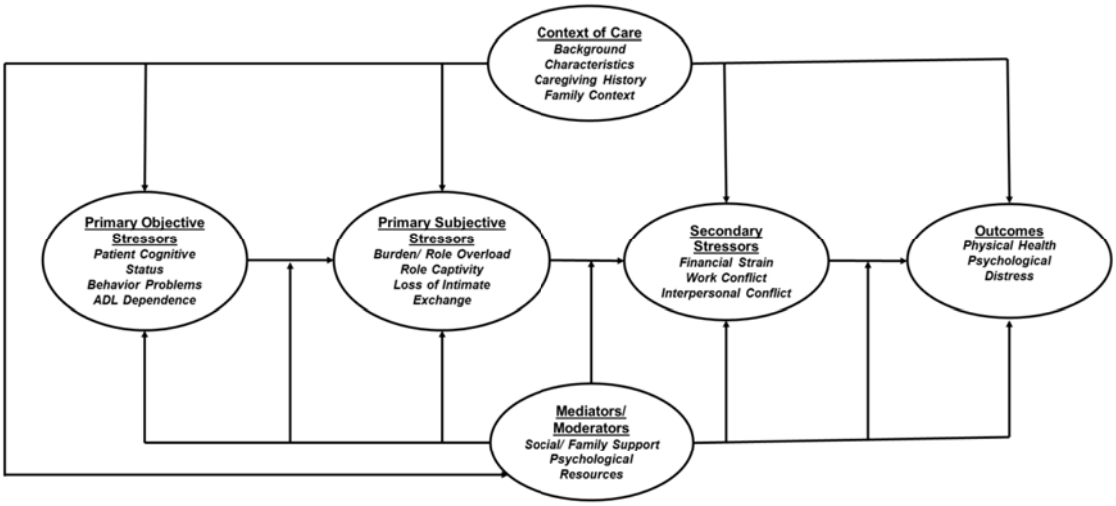

Figure 2. The Stress Process Model of caregiver functioning.

Asserting that mere identification of factors and circumstances which may be associated with caregiving stress is not sufficient, the SPM aims to explain their origin and interrelationship (Pearlin & Bierman, 2013). Pearlin and colleagues posited that the stress process consists of four general domains (the background and context of stress, the stressors, the mediators of stress, and the outcomes or manifestations of stress), each of which in turn includes multiple components (Pearlin et al., 1990). The inclusion of contextual characteristics, such as caregiver age, gender, educational, occupational, and economic attainment is the first defining characteristic of this model. The authors argued that these variables play an important role in shaping individuals' reactions to stressful pressures of providing care because they determine the types of personal and social resources that may be available to deal with the stressors. Family context of the care provision, such as the relationship with the care recipient, including relatedness (spouse, offspring, in-law) and quality of the relationship prior to assuming caregiving duties are also included as important determinants of background/ context of care. This also includes,

in the context of family functioning, such caregiving variables as hours per week spent providing care and its total duration (in months/ years) as indicators of chronicity of the stressors (Pearlin et al., 1990).

Stressors, which are considered the central part of the model, are divided into primary and secondary. These labels are not meant to imply that some stressors are more important than others. The authors conceived that the demands of caregiving, such as the cognitive status of the AD patient, with the resultant difficulties in memory and communication, as well as any concurrent presentation of disruptive behavior or difficulties with performing activities of daily living, determine an initial "objective" stress load for the caregivers. These variables can be measured with validated instruments (e.g., the Mini-mental Status Examination, Neuropsychiatric Inventory, or ADL/ IADL questionnaires) (Cummings, 1997; Folstein, Folstein, & McHugh, 1975; Lawton & Brody, 1969), which allow clinicians to draw inferences about the types of attention and care a patient may need, indicating demands placed on the caregiver. As such, primary objective stressors are a direct result of the care recipient's illness. Primary subjective stressors, on the other hand, are caregivers' emotional reactions to various care demands, referring to their perception of care demands as exhausting, distressing, or burdensome. Included here is also any potential loss of emotional contact or intimacy with the care recipient due to the care recipient's illness (Pearlin et al., 1990; Zarit, 1990).

The perceived burden, strain, and stress of care provision may spread to other life domains, and within the Stress Process Model these are referred to as secondary stressors (since they are directly impacted by the two primary stressor types). Secondary stress can include work conflict, when providing care impacts on the frequency or quality of

employment; financial strain, such as reduction in income and increased expenses due to caregiving duties and responsibilities; or interpersonal conflict and tension, including that with colleagues, friends, or family members (Gaugler, Kane, & Langlois, 2000; Pearlin et al., 1990). Even though the term "secondary" is used to refer to these types of stress, they in and of themselves have been shown to serve as potentially important predictors of negative outcomes (Pearlin et al., 1990; Zarit, 1990).

The next link in the stress model pathway is global outcomes, which can include indicators of physical health (e.g., hypertension, increased infections, etc.) and mental health, such as depression, anxiety, or anger. Other outcomes can be conceptualized in the context of the model, however, including care recipient factors (i.e., institutionalization), or those related to caregivers, such as quality of care provision (Kane & Kane, 2000; Kosloski & Montgomery, 1995).

The final component of the SPM includes mediating or moderating factors which can also impact the propagation of stress anywhere along the causal pathway. These factors include caregiver's individual psychological resources (e.g., sense of mastery, coping style and skills) as well as social support. Components of social support may refer to a variety of sources—those obtained from the community, friends, or the family. It could also include objective (e.g., the amount of support received), as well as subjective indicators of support, such as caregiver's perception of adequacy of support and assistance offered by the family, or overall functioning, closeness, or satisfaction within the family (Cantor, 1994; Pearlin et al., 1990).

The SPM permits exploration of multiple groups of predictors (i.e., environmental, socioeconomic, demographic, and psychosocial factors) and interactions between latently constructed groups of predictors (Hilgeman et al., 2009). Compared to other models, the SPM is more complete in that it includes positive resources of the individual and their environment (e.g., social and family support). It provides a basis for the exploration of complex interrelationships between various factors that influence caregiver functioning in multiple domains. Furthermore, the authors encouraged the use of the Model not as a "literal reflection of realities and the pathways that join them" (Pearlin et al., 1990, p. 591), but as a framework which can be built upon to explore interconnections which are still unclear.

Haley and colleagues (2003) built upon this idea to investigate the relationship between depression and life satisfaction among 80 spousal caregivers of terminally ill patients with lung cancer or dementia who were in hospice care. They found that caregivers who appraised caregiving tasks as less stressful and who perceived benefits in caregiving had lower depression and greater satisfaction with life, even after controlling for background characteristics and primary objective stressors (Haley, LaMonde, Han, Burton, & Schonwetter, 2003). Findings such as these, when applied to understudied and vulnerable populations, can inform the development and implementation of empirically-driven interventions. By uncovering the importance of subjective appraisal of one's caregiving experience in a positive and accepting way, researchers have developed mindfulness-based cognitive therapy for cancer patients, survivors, and their caregivers, which has proven efficacious in fostering positive psychological outcomes and reducing burden (Rouleau, Garland, & Carlson, 2015; Wood, Gonzalez, & Barden, 2015). Grounded in the Stress

Process Model, a study by Mitrani et al. (2006) assessed sociodemographic and mental health variables, along with measures of social and family support in a sample of 181 dementia caregivers in the United States. The relationship between primary stressor (objective burden reported by a caregiver) and outcome (caregiver's report of anxiety, depression, and perceived health) was partially mediated by family functioning, which also explained a significant amount of variance in caregiver distress beyond that predicted by sociodemographic and care provision variables (Mitrani et al., 2006). These important findings highlight not only the explanatory power of Pearlin's model, but also the pivotal role of family dynamics in reducing—or augmenting—caregiver distress.

1.6 Caregiver Functioning and Family Dynamics

Due to their pivotal role in providing care to individuals with dementia, families are considered the primary therapeutic agents in dementia care (Gitlin & Schulz, 2012; Pruchno & Gitlin, 2012). Among the factors that influence informal caregiver adjustment, family functioning variables have emerged as some of the most salient. Interpersonal conflict between members of families affected by dementia has been associated with significantly increased caregiver depression and anger (Semple, 1992) as well as higher perceived burden and more poor overall mental health (Strawbridge & Wallhagen, 1991). Conversely, high cohesion, or unity, within the family unit has been associated with reduced caregiver depression and burden (Torossian & Ruffins, 1999).

There is an increasing amount of evidence that in the context of family systems theory (Minuchin, 1974), family factors such as marital cohesion, communication patterns,

boundary ambiguity, and family adaptability are related to emotional functioning of informal caregivers (Boss, Caron, Horbal, & Mortimer, 1990; Deimling, Smerglia, & Schaefer, 2001; Rankin, Haut, & Keefover, 2001; Speice, Shields, & Blieszner, 1998). Additionally, quality caregiver-care recipient relationship prior to diagnosis is associated with increased satisfaction with care provision (López, López-Arrieta, & Crespo, 2005). Numerous family interaction patterns are believed to contribute to CG distress, including emotional detachment or over-involvement, negativity, and ineffective conflict resolution (Mitrani & Czaja, 2000). However, factors such as high family support, validation of the caregiver's leadership, and collaborative decision-making in the family may serve a protective function in shielding caregivers from the negative effects of stress (Mitrani et al., 2006).

Structural family theory (Minuchin, 1974) has been employed as an effective tool in order to better understand the underlying dynamics of family functioning and the general mechanisms by which the family affects the caregiver. This theoretic approach conceptualizes the family as an organism which is governed by structures, or repetitive patterns of interaction. These structures regulate the manner in which family members interact across multiple domains and settings, for example in assigning roles and expectations, managing disagreements and conflicts, and negotiating closeness or distance (Minuchin, 1974). Problematic structures are viewed as the root cause of symptoms in individual family members; a family is regarded as functional or dysfunctional depending on its ability to adapt to various stressors, whether developmental, intra-family, or external . In cases when a disruptive stressor is placed on the family, such as when a person is affected by dementia, the family system can respond by either adapting to the changing

circumstances and needs of family members, or fail to adapt and leave vulnerable family members exposed to risk (Minuchin, 1974).

With its basis in the family systems theory, the Circumplex model of Marital and Family Systems (Olson, 2000; Olson, 2010) has been used as a way to quantitatively study the underlying patterns of family functioning in caregiver populations in order to bridge the gaps between theory, research, and practice. The Circumplex model posits that balanced family systems tend to be more functional compared to unbalanced systems. The measure of balance within the family unit is assessed using the Family Adaptability and Cohesion Evaluation Scales (FACES) along three dimensions: cohesion, flexibility, and communication, though satisfaction with family functioning is also an important construct within the theory (Olson, 2010).

Cohesion refers to affection and emotional closeness or togetherness between family members. It is thought to exist on a continuum which ranges from disengagement (i.e., low cohesion), indicated by emotional separateness within the family, seldom engaging in activities together, not getting along, to enmeshment (i.e., extreme cohesion), when family members may feel pressured to spend excessive time together or are overly interdependent and lack individuation from the family (Olson, 2011; Olson, 2010). Problems may arise due to the inability of a family to balance autonomy and intimacy. Members of disengaged families have difficulty turning to one another for support during stressful times, while highly enmeshed families may demand strict loyalty and leave little space for privacy or outside interests. Between the two extremes lies a healthy balance of family cohesion, where members are able to bond emotionally, share decision making and provide support for each other, and function independently when needed (Olson, 2010). It

is important to note, however, that unbalanced family systems according to the Circumplex model are not necessarily dysfunctional (Olson, 2000). This is particularly true for families from certain religious (e.g., Mormon, Amish, Hasidic) and ethnic groups (i.e., Latino/ Hispanic), as their normative expectations may differ from Western standards of autonomy and freedom.

Family flexibility is defined as "as the quality and expression of leadership and organization, role relationship, and relationship rules and negotiations" (Olson, 2011, p. 65). Again, this dimension of family functioning is thought to exist on a continuum. On one end, families with low flexibility, referred to as rigid, have inflexible expectations, roles, and rules, as well as excessive consequences when family members deviate from them. Such rigid family systems often may exhibit narrow behavioral repertoire, limited negotiations, and strictly defined roles imposed by a highly controlling leader; when faced with increasing stress they tend to become even more inflexible and rigid (Olson & Gorall, 2006). More balanced level of flexibility involves democratic or egalitarian leadership which allows room for negotiation of roles and expectations with other members (e.g., children), permits sharing of roles and changing of rules when appropriate. The opposite end of the spectrum is considered chaotic, such that families with overly high flexibility may lack clearly defined leadership, be more disorganized and even fail to accomplish everyday tasks (Olson, 2011). In terms of possible clinical interventions, rigid family structures can often benefit from learning and applying better problem solving skills and joint or shared decision making, while chaotic systems may need to increase internal structure and order before being able to enjoy the benefits of improved problem solving skills (Olson, 2000).

The third dimension of the Circumplex model is family communication. It is considered critical for facilitating movement on the two previous dimensions of cohesion and flexibility. Family communication is measured by evaluating members' perception of speaking and listening skills (e.g., empathy, attentive listening), clarity, respect, regard (e.g., problem solving), and self-disclosure (e.g., sharing of feelings) in their daily interactions. Having good communication skills enables families to more clearly express the type of relationship they would like to have on cohesion and flexibility (Olson, 2000). Families that find themselves on either extreme along these dimensions tend to have poor communication, but increasing positive communication skills can facilitate system change by increasing awareness of other members' preferences and needs.

Measuring family satisfaction with existing levels of cohesion, flexibility, and communication is an important component of the Circumplex model. Lower family satisfaction has been correlated with poor communication within the family, as well as unbalanced family functioning (Olson, DeFrain, & Skogrand, 2010). In the context of dementia, caregivers with high satisfaction reported significantly less burden, less reactivity to memory and behavior problems, better problem solving skills, and more effective communication compared with the low caregivers, even after accounting for length of caregiving, and care recipient disease severity and daily functioning, supporting the notion that relationship satisfaction may be an important contributor to caregiver burden (Steadman, Tremont, & Davis, 2007).

Measurement models rooted in structural family theory have been proposed as an effective tool for illuminating the role of the family in caregiver stress processes, since they incorporate the multidimensional nature of the family experience and provide a paradigm

for better understanding the mechanisms by which the family affects the caregiver (Mitrani et al, 2006). The Circumplex model of family functioning has been used in over 1200 research studies, and has gathered ample empirical support (Kouneski, 2001; Olson 2010). It has been effectively employed to gain a better understanding of family processes in a variety of caregiver populations, including those affected by neurological disorders. Using a translated version of the FACES-III assessment instrument (Olson, 1986), an Italian research group of Tramonti and colleagues (2015) evaluated mental health correlates of family functioning in a sample of thirty caregivers of hospitalized individuals with severe brain injury. Despite the relatively small sample size, family cohesion and adaptability was found to positively correlate with caregivers' quality of life and perceived social support. A particularly interesting finding was the reportedly higher emotional burden and a stronger desire for family adaptability in adult child caregivers who looked after their brain injured parents (Tramonti et al., 2015), indicating differential perceptions of family functioning depending on familial relationship to the patient.

In one of the first research applications of the Circumplex model in Latin America, Lehan and colleagues (2013) investigated the relationship between family dynamics variables in 38 pairs of individuals with TBI and their family caregivers from Mexico using the latest version of the FACES instrument (FACES-IV; Olson, 2010). They discovered that both caregivers and TBI survivors reported relatively high levels of family satisfaction and communication, which were related to better communication and greater family satisfaction. Trujillo et al. (2015) reported that in a sample of dementia caregivers from Argentina the relationship between family functioning (evaluated using the FACES-IV) and caregiver mental health was mediated by their coping and attitudes, such as optimism,

resilience, and coherence (Trujillo et al., 2015). In a study conducted in Colombia with a sample of dementia caregivers, Sutter and colleagues found a significant association between family flexibility and depression. Hierarchical multiple regression analyses, controlling for caregiver background variables, revealed that higher perceived stress and burden in family caregivers was significantly predicted by lower family communication and empathy, respectively (Sutter et al., 2014). These pioneering studies indicate that the Circumplex model (Olson, 2010) is a useful tool in assessing family functioning in families affected by neurological conditions, and can be effectively employed to study caregiver perception of family dynamics in Latin American countries, where close family connections are highly valued (Falicov, 2013).

The impact of AD extends beyond the immediate family and may extend two or three generations, exerting disruptive influence on cohesion and communication processes and negatively affecting family ties and mental health (Tramonti et al., 2013). Undoubtedly, while identifying cases of caregiver burden in situations of evident overload is important, it is not sufficient for proper understanding of the complex nature of circumstances which may facilitate the negative cascade of events which leads to burnout. Accounting for the underlying family-related processes provides a richer context for appreciation of the complex nature of caregiver dynamics, and better informs the development of appropriate, culturally-informed interventions to maintain and improve the quality of family-based care provision to individuals with dementia.

1.7 Quality of Family-Based Care Provision

Another important, but less studied, aspect of caregiver functioning is the provision of quality care to their loved one with dementia. Until relatively recently, the concept of quality of care in the context of dementia was studied from institutional (i.e., hospital and long term treatment facility) points of view, with a focus on such organizational outcome measures as cost of care provision, adherence to established practice guidelines, rates of readmission or patient mortality (Chodosh et al., 2007; Stelfox & Straus, 2013). While these variables are undoubtedly an important topic of study, they have relatively little practical bearing on day to day functioning of those dementia patients who are not institutionalized, and instead receive care at home from their family members (Martire, Schulz, Wrosch, & Newsom, 2003; Schulz & Martire, 2004).

Family members are driven to provide care to their loved one affected with dementia for many reasons. In the context of a particular culture, they may be motivated by their cultural norms of obligation expected from the children or spouse. For example, from early on children may be taught that they are expected to assist their elderly parents in the future, as part of family values promoted in their ethnic group (Binstock, George, Cutler, Hendricks, & Schulz, 2011). In the case of spouses, older couples take their marriage vows (i.e., "…in sickness and in health") seriously, and thus may care for their sick partner without much doubt or concern for own well-being (Harris & Long, 1999). Family members may offer help because of their desire to reciprocate for past assistance provided by the care recipient, or because of their love and affection. Providing care to a person with dementia is a complex endeavor, which requires caregivers to manage multiple roles and tasks at once.

A nationwide survey of caregivers identified six general areas of tasks involved in providing informal care (Keating, Fast, Cranswick, & Perrier, 1999). Given the progressive nature of the dementing illness, one of the most important aspects of care provision is in the domain of personal care, and involves assistance with such tasks as eating, taking medication, dressing, bathing, mobility (e.g., walking, getting out of bed, etc.), and toileting. Another category of care provision involves help with household activities, such as housework (e.g., preparing and cleaning up after meals, cleaning and doing laundry, washing floors and vacuuming, making beds, etc.) and household maintenance (e.g., minor repairs, yard work, etc.). Assistance with shopping and transportation, such as helping with running errands and with shopping, and financial management (e.g., paying bills, balancing bank accounts, and filing taxes) are another two important categories of care provision for informal caregivers. A less tangible category of care provision is that of emotional support to the care recipient, which includes providing opportunities for socialization, self-affirmation and self-actualization, and overall assistance with maintaining social interaction. Lastly, caregivers help with monitoring overall care provision, which may include making sure that the care recipient's needs are satisfied, and quality of services are provided by, for instance, scheduling or coordinating caregiving tasks (e.g., hiring professional help, organizing a care schedule) (Cranswick & Dosman, 2008; Keating, Fast, Dosman, & Eales, 2001; Smale & Dupuis, 2004).

In the last two decades the concept of informal (i.e., family-based) care provision has gained attention of researchers interested in improving various aspects of functioning of dementia patients and their caregivers. Concurrently, scientific literature has exhibited a shift from its initial focus on *quantity* of care provision, such as accounting for the amount

of resources (e.g., time, finances, etc.) expended on caregiving tasks (Ory & Duncker, 1992), to investigating correlates and predictors of *quality* of informal care provision. Focusing solely on the quantity, or the amount, of care provided fails to take into account other important aspects of the patient-caregiver relationship (Morrow-Howell, Proctor, & Rozario, 2001).

Current scientific literature conceptualizes quality of care in dementia as a complex and multidimensional construct (Christie et al., 2009). Traditionally, quality of informal care referred to the degree to which the care recipient's needs were satisfied in terms of basic (e.g., eating, bathing, dressing) and instrumental (e.g., preparing meals, handling finances) activities of daily living (Skinner et al., 1999). From a qualitative view point of meeting and satisfying these needs, a caregiver may engage in a range of practices—from acting abusively and neglectfully towards their care recipient, therefore in no way satisfying their needs, to providing just enough care to satisfy the needs, all the way to providing the best care possible by being thorough, responsive, considerate, and respectful in meeting the patient's basic and instrumental needs (Morrow-Howell, Proctor, & Dore, 1998). This component of care provision refers to its *adequacy*.

A related, but separate concept in quality of care provision is that of *potentially harmful behaviors* (PHB) exhibited by caregivers. Such behaviors may include actions consistent with psychological (e.g., screaming, yelling, insulting, etc.) or physical (e.g., hitting, slapping, etc.) maltreatment of the care recipient, but do not necessarily prevent provision of adequate care. Seemingly paradoxically, a caregiver may engage in any or all of aforementioned PHBs, yet still provide adequate help to meet the family member's needs in regards to activities of daily living (Christie et al., 2009; Williamson & Shaffer, 2001).

In regards to quality of care provision, caregiver abusive and potentially harmful behavior has been of great interest to researchers, since individuals with dementia represent a particularly vulnerable population (Cooney, Howard, & Lawlor, 2006). Such factors as dementia patients' worse cognitive status (Weerd & Paveza, 2006) and physical and psychological aggression (Wiglesworth et al., 2010), and caregivers' longer duration of providing care to a person with dementia (Cooper et al., 2009) have emerged as important predictors of engagement in potentially harmful or abusive behaviors. Equally importantly, caregiver engagement in PHBs has been linked to their own mental health functioning. Studies have shown that caregivers are more likely to engage in abusive or harmful behaviors towards their loved one with dementia when they experience higher levels of anxiety (Cooper et al., 2010), anger (Macneil et al., 2010), burden (Lee & Kolomer, 2005), or depression (Beach et al., 2005; Shaffer, Dooley, & Williamson, 2007). On the other hand, those caregivers who are more forgiving towards dementia patient's disruptive behaviors tend to engage in fewer potentially harmful behaviors (Cheng, Ip, & Kwok, 2013)

The third component of quality of care provision identified by the literature is that of *exemplary care*, referring to the portion of the care spectrum that is very high in quality. Such "high quality care", therefore, is not only adequate (i.e., satisfies the care recipient's needs in terms of basic and instrumental activities of daily living), but also includes the requisite component of communicating respect, concern, and thoughtfulness about the recipient's well-being (Harris, Durkin, Allen, DeCoster, & Burgio, 2011). Empirical evidence suggests that sensitivity, reciprocity, and respect in care provision may play a larger role in delivery of high quality care than its amount or adequacy (Dooley, Shaffer,

Lance, & Williamson, 2007). Provision of this type of care and the corresponding interpersonal dynamics and interaction have been shown to forecast well-being of both the caregivers and care recipients, such that subjective perception of sensitivity in care provision predicted levels of depression and sense of mastery (Martire et al., 2003; Wolff & Agree, 2004). Caregivers who engaged in exemplary, person-centered, high quality care provision indicated lower levels of burden (Harris et al., 2011). Conversely, conflicts among caregivers and their patients are more likely if the latter feel disrespected, demeaned, less competent or in control (Clark & Stephens, 1996; Matire, Stephens, Druley, & Wojno, 2002).

The concept of exemplary care has been introduced to the scientific study of caregiver care provision in dementia relatively recently (Dooley et al., 2007). As a result, at present there is a lack of knowledge in regards to its relationship to other aspects of caregiver functioning, such as those related to mental health or family dynamics. The few studies conducted on the topic of exemplary care provision by dementia caregivers have been conducted in the context of predominantly Anglo-Saxon cultures of North America (Harris et al., 2011; Smith et al., 2011), and very little is known about this component of care provision in other parts of the world, such as Latin America. For the purpose of the current study, the concept of "quality of care" will focus solely on provision of exemplary care by family caregivers of individuals with dementia (Dooley et al., 2007) in the context of Latin America.

1.8 Dementia Caregivers in Latin America

The majority of studies with caregivers of individuals with dementia have been conducted in English-speaking, Western countries (Brodaty & Donkin, 2009). Consequently, assumptions about the nature of the caregiving experience based on research results obtained with individuals from these countries is not necessarily reflective or applicable to other ethnic and cultural groups, and may also lead to inappropriate and ineffective interventions and services (Henderson, 1996; Janevic & Connell, 2001). Despite the increasing prevalence of dementia in Latin America, there is still a relative paucity of research conducted with dementia caregivers in the region.

Superficially, the profile of a dementia caregiver in Latin America is not dissimilar to that described in the Western literature: they are most frequently females, spouses or adult children of the care recipient, between 40-65 years of age (Brodaty & Donkin, 2009). A more in-depth look, however, reveals that Latin American dementia caregivers are also very different from their counterparts in the developed countries. They tend to provide more daily care (often for eight hours per day or more), have less knowledge about dementia and its course, have more unmet needs, and possess significantly fewer economic resources (Cardona-Arango, Segura Cardona, Berbesí Fernández, Ordoñez Molina, & Agudelo Martínez, 2011; Cerquera Córdoba, Granados Latorre, & Buitrago Mariño, 2011; Espín Andrade, 2008; Espín Andrade, 2012; Gratao et al., 2010; Jofré Aravena & Sanhueza Alvarado, 2010; Llibre Guerra, Guerra Hernández, & Perera Miniet, 2008; Prieto, 2007). Consequently, all of these elements are risk factors which may predispose dementia caregivers in the region to experience higher psychological morbidity. Dementia caregivers in Latin America report experiencing significantly lower quality of life and higher levels of

depression than the general population (Arango-Lasprilla et al., 2010b; Posner et al., 2015). Previous studies have found significant association between lower cognitive functioning in dementia patients in Latin America with higher levels of caregiver depression and burden (Arango-Lasprilla, Moreno, Rogers, & Francis, 2009). The documented lack of access to health care resources in Latin America, including support services, residential programs, and caregiver treatment or interventions, suggests that many family needs are less likely to be met, creating further strain on the family system (Arango-Lasprilla et al., 2010a; Fuentes, Baker, Markello, & Wood, 1999; Lehan, Arango-Lasprilla, Macias, Aguayo, & Villaseñor, 2012).

Important differences also exist between Western and Latin American caregivers in terms of social and family factors. Caregivers from this region are more likely to be religious, collectivist, have strong familial ties and a sense of obligation to support family members who are sick or in need (Arciniega, Anderson, Tovar-Blank, & Tracey, 2008; Pyke & Bengtson, 1996). Indeed, family-based caring for the elderly is embedded in the very culture of Latin American society (Arango-Lasprilla et al., 2009), and is seen as a major priority regardless of its economic or psychological cost on the family (Reed et al., 2014). Institutionalization of the person with dementia is not considered as a viable option out of concern that doing so may be perceived as an admission of one's inability to meet cultural expectations to care for a sick family member, and incur stigma, shame, and social judgment from the community (Cooper et al., 2010; Lykens et al., 2014). Consequently, Latino families care for their loved ones with dementia at home for longer periods of time before succumbing to the need to search professional help or institutionalization (Talamantes, 2011). On the other hand, due to very high value placed on *familismo*, or filial

piety, caregivers may rely on a wider network of support from extended family and friends to care for the elderly (Valle, Yamada, & Barrio, 2004). This cultural factor may have a protective role of buffering caregivers against psychological distress (Knight et al., 2002; Neary & Mahoney, 2005).

The prevailing cultural views and normative expectations shape individuals' attitudes and behaviors in the context of informal dementia care. Dilworth-Anderson and Gibson (2002) reported that cultural values and beliefs among different ethnic groups affect the meanings they assign to dementia. These cultural meanings and interpretations in Latin America can result in consequences such as believing that having dementia is the result of having "bad blood", and creating barriers to seeking assistance outside the family system (Dilworth-Anderson & Gibson, 2002; Gallagher-Thompson et al., 1997). The converse may also occur—various cognitive and behavioral manifestations of AD may be interpreted as "normal", given the cultural belief that these symptoms are to be expected as part of the aging process (Dilworth-Anderson, 2012). This view that aging brings about "absent-mindedness" and senility can result in delayed physician consultation, by as many as seven years (Clark et al., 2005). Thus, cultural context in Latin America plays an important role in potentially creating a cascade of events which may include disparities in prompt diagnosis and delayed implementation of intervention or respite services for patients and their families. In many cases this, as well as the fact that such services are not even provided, may create a negative impact on caregivers' physical and psychological well-being, ultimately affecting their functioning and the possibility to consistently provide the best care to their loved one with dementia (Sánchez-Guzmán, Paz-Rodríguez, Espinola-Nadurille, & Trujillo-De Los Santos, 2015).

Very few studies to date have examined the variables related to quality of care provision in Latin America; the studies that have been carried out focused primarily on negative aspects of care provision. In an important line of research with neurological patients and their caregivers in Mexico, Paz-Rodríguez and colleagues reported that 39% of informal caregivers engaged in potentially harmful behaviors of a psychological nature (e.g., speaking to or treating the person in a way that causes emotional pain or distress, such as insulting or ignoring them), and around 4% were found to have engaged in physical maltreatment of their care recipient. Further, these negative aspects of informal care provision to individuals with neurological conditions in Latin America were significantly related to caregiver perception of burden and stress (Paz-Rodríguez & Sánchez-Guzmán, 2011; Sánchez-Guzmán et al., 2015), suggesting these psychological constructs as important risk factors for identifying those caregivers who may benefit the most from interventions aimed at improving their mental health functioning and quality of care provision.

1.9 Study Objectives

To date there has been very little research focus on exemplary care provision by informal dementia caregivers in Latin America (Panyavin et al., 2015). Even less is known about the pattern of relationships between the constructs of family dynamics, mental health functioning, and provision of quality care in informal caregivers of individuals with dementia in this global region. The largest empirical studies of dementia caregiver functioning in Latinos have been carried out with caregivers living in the United States (Lykens et al., 2014). Given the enormous social and economic impact of dementia in Latin

America (Wimo et al., 2013), implications of research focusing on the interrelationship of dementia caregiver variables could be numerous. By uncovering the up until now unknown relationships between potentially modifiable factors (such as family dynamics) and outcomes which have important influence on wellbeing of dementia patients, their caregivers, and their families, it is possible to create more effective, empirically-derived and culturally appropriate intervention strategies to improve their functioning. Ultimately, knowledge obtained through research projects which address these topics would serve to maintain or improve quality of life of the families affected by dementia, avoid or delay institutionalization of dementia patients, and mitigate costs and burden on the health care system.

Many family caregivers of individuals with dementia experience mental and physical health problems due to informal care demands (Sánchez-Guzmán et al., 2015). This is manifested in elevated levels of burden, depression, and anxiety, and reduced social support and satisfaction with life (Pinquart & Sorensen, 2006). Family functioning plays a pivotal role in determining caregiver adjustment to multiple stressors identified in providing informal care to a dementia patient (Mitrani et al., 2006). Provision of person-centered, exemplary care, a recently identified and relatively little studied component of quality of care provision, has the potential to be an important outcome variable in the context of family systems theory and the Stress Process Model (McClendon & Smyth, 2013). The interrelationship between these constructs has not been well studied in Latin America. To address the key gaps in the literature, the present study established the following objectives and hypotheses:

1. To describe principal sociodemographic, caregiving, psychosocial, and family functioning variables of family caregivers of individuals with dementia in Latin America, and determine a relationship between caregiver sociodemographic, care provision, and mental health functioning variables.

   $H_{1.1}$: Lower indices of mental health functioning (i.e., levels of depression, anxiety, satisfaction with life, and perceived burden) will be significantly associated with higher caregiving load (i.e., time spent providing care per week and months/ years).

   $H_{1.2}$: Objective primary caregiving stressor (lower patient cognitive status) will be significantly related to higher caregiver burden and worse mental health functioning.

2. To examine the multivariate pattern of relationships between caregiver family functioning and mental health.

   $H_{2.1}$: Healthy family dynamics will be significantly related to better indices of caregiver mental health.

   $H_{2.2}$: Healthy family dynamics will predict lower caregiver depression, anxiety, burden, and better satisfaction with life.

3. To examine the influence of family dynamics on quality of care provision, as measured by the Exemplary Care Scale (Dooley et al., 2007), and identify sociodemographic and family variables that best predict better quality of care.

   $H_{3.1}$: Healthy family dynamics will be significantly associated with provision of high quality informal care.

$H_{3.2}$: Healthy family functioning will significantly predict higher quality of informal care, even after controlling for background and caregiver variables.

4. To test a theory-driven model based on Pearlin's (1990) conceptualization of caregiver stress processing, which evaluates the interrelationship between dementia caregivers' background characteristics, patient cognitive functioning, caregiver mental health, and family dynamics, with provision of exemplary care as the ultimate outcome (Figure 3).

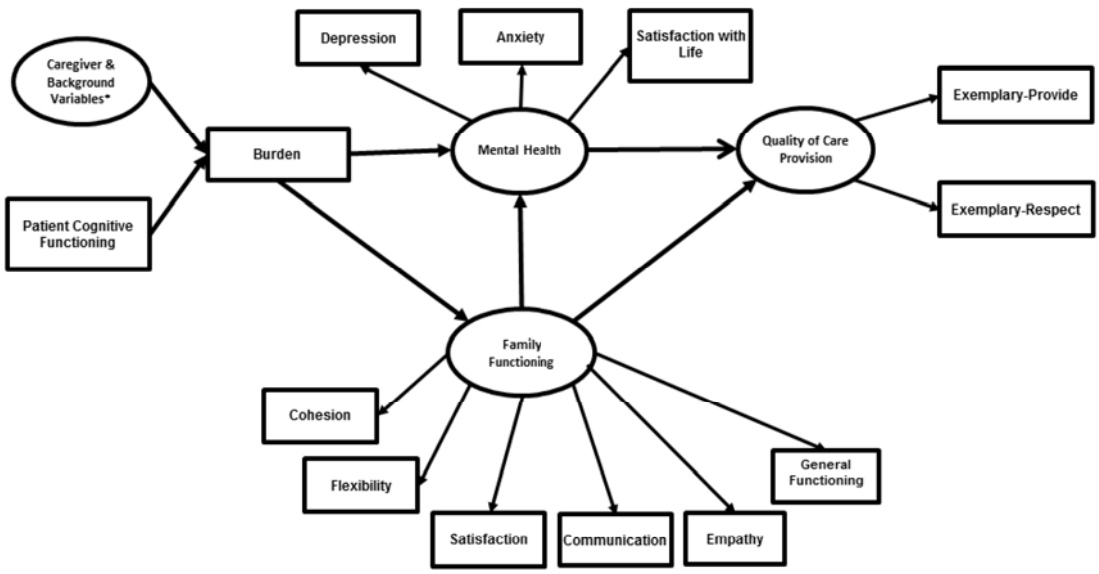

Figure 3. The hypothesized theoretical model for the study.

$H_{4.1}$: Background and caregiver variables (i.e., more time spent providing care, older age), together with lower patient mental status, will significantly relate to higher caregiver subjective burden.

$H_{4.2}$: Greater caregiver burden will significantly negatively impact on to caregiver family functioning.

$H_{4.3}$: Greater caregiver burden will significantly negatively impact onto caregiver mental health.

$H_{4.4}$: Healthier family dynamics and better indices of mental health functioning will be significantly positively associated with high quality of informal care.

$H_{4.5}$: The relationship between family dynamics and quality of care will be mediated by mental health.

2 Method

2.1 Participants

The sample was comprised of caregivers of individuals with dementia from Argentina and Mexico. Caregivers were eligible to participate in this study if they: (a) were related to the person with dementia; (b) self-identified as the primary caregiver of the patient; (c) had been providing care for at least three months; (d) were knowledgeable about the patient's family and medical history; and (e) had no self-reported history of substance abuse, neurological and psychiatric disorders, or learning disabilities. Participants were recruited from the National Institute of Neurology and Neurosurgery (Mexico, n = 20), and the Neurosciences Institute of San Lucas (Argentina, n = 110), with a total of 130 caregivers meeting inclusion criteria. Data collection took place between September of 2013 and June of 2015.

The sample had an average age of 56.9 years (SD = 13.5) and was 76% female (n = 99) (Table 1). The average education level of the sample was 13.7 years (SD = 4.8), with 30% and 40% of the sample reporting having completed college education and high school, respectively. The caregivers were mainly spouses or children of the person with dementia (44.6% and 47.7%, respectively), with 76.9% of the sample reporting being married, 9.2% single, and 7.7% divorced or separated. Observation of reported family income levels revealed that 20% of the caregivers earned between one and two times minimum wage, 38.5% earned the equivalent of between two and three times the minimum wage, 24.6% between three and four times minimum wage, and 16.9% more than four times minimum wage. Caregivers reported providing care for an average of 47.1 months (SD = 29.6), and spending 69.8 hours per week (SD = 36.1) on care provision. The care recipients' average

score on the Mini-Mental Status Examination (MMSE) was 20.0 (SD = 3.23), with a range of 10-24. The clinical diagnosis of probable Alzheimer's disease was made according to established standards (American Psychiatric Association, 2000) by the treating neurologist, who also supplied the patient's MMSE score (Folstein et al., 1975) at the time of caregiver evaluation.

Table 1. Caregiver sociodemographic characteristics.

Sociodemographic Characteristics	Family Dementia Caregivers (N=130)
Age, years, mean (SD)	56.9 (13.5)
Gender (% female)	76.2
Marital Status (%)	
Single	9.2
Married	76.9
Divorced/Separated	7.7
Other	6.2
Education (%)	
Elementary/primary	17.0
Some high school	4.6
Completed high school	40.0
Technical studies	6.9
Some college	1.5
Completed college	30.0
Socio-economic level (%)	
1-2 (times the minimum wage)	20.0
2-3	38.5
3-4	24.6
4+	16.9

There were no differences between the participants from Argentina and Mexico in terms of gender ($p = 0.66$), age ($p = 0.61$), type of relationship with the care recipient ($p = 0.70$), marital status ($p = 0.23$), education ($p = 0.15$), months spent providing care ($p = 0.96$), or the MMSE score of the patient ($p = 0.53$). Significant difference between the participants from the two countries was revealed on the variable of hours per week spent

providing care, $t(128) = 2.94$, $p < .01$, with caregivers from Mexico (M = 109.1, SD = 70.1) reporting greater weekly investment in providing care to their family member with dementia than those from Argentina (M = 62.7, SD = 18.9). Since the participants from the two locations were general comparable in terms of sociodemographic variables, they were treated as a single group for the purpose of statistical analysis.

2.2 Instruments

A researcher-created questionnaire was used to gather demographic information from dementia caregivers. The participants completed several measures that assessed their mental health functioning, family dynamics, and quality of informal care. All of the instruments employed in the present study have been successfully utilized as predictor or outcome measures in studies with caregivers of individuals with dementia reported in the literature before.

Spanish-language versions of the Patient Health Questionnaire-9 (PHQ-9), Generalized Anxiety Disorder Scale (GAD-7), Satisfaction with Life Scale (SWLS), Zarit Burden Interview (ZBI), Family Adaptability and Cohesion Evaluation Scale-Fourth Edition (FACES-IV), Family Satisfaction Scale (FSS), Family Communication Scale (FCS), Relationship-Focused Coping Scale (RFCS), General Functioning subscale of the Family Assessment Device (FAD-GF), and Exemplary Care Scale (ECS) were used, and are described in greater detail below.

2.2.1 Mental Health Functioning

Patient Health Questionnaire-9 (PHQ-9)

A 9-item module of the Patient Health Questionnaire was used to measure caregiver depression (Kroenke, Spitzer, & Williams, 2001). Responses are provided on a Likert scale (ranging from 0 to 3, "not at all" to "nearly every day", respectively), with a possible range of scores from 0-27. Higher scores on this instrument indicate greater levels of depression. The version used in this study has demonstrated good validity and internal consistency (α =.92) in assessing depression in Spanish speakers (Diez-Quevado, Rangil, Sanchez-Planell, Kroenke, & Spitzer, 2001; Wulsin, Somoza, & Heck, 2002; Donlan & Lee, 2010). Cronbach's alpha for the PHQ-9 in this sample was $\alpha = 0.88$.

Generalized Anxiety Disorder Scale (GAD-7)

The GAD-7 is a self-administered screening and severity measure used to assess generalized anxiety disorder (Spitzer, Kroenke, Williams, & Lowe, 2006). It consists of 7 Likert-type questions (ranging from 0-3, "not at all", "several days", "more than half the days", and "nearly every day"); scores of 5, 10, and 15 are taken as the cutoff points for mild, moderate, and severe anxiety, respectively. Internal consistency in this sample was good ($\alpha = 0.90$).

Satisfaction with Life Scale (SWLS)

SWLS is a five-item self-report measure of subjective perception of life satisfaction. It employs a 7 point Likert scale (response options range from 1 to 7, "strongly disagree" to "strongly agree", respectively), with higher scores indicating higher overall life satisfaction (Pavot & Diener, 1995). Spanish-language version of this scale has demonstrated good

psychometric properties, with reported internal consistency of .75 (Arango-Lasprilla et al., 2014). Internal consistency of SWLS in this sample was excellent (α = 0.92).

Zarit Burden Interview (ZBI)

The Zarit Burden Interview is a 22-item, self-report questionnaire that evaluates the caregiver's feelings of guilt, psychological burden, and social life (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005; Zarit, Reever, & Bach-Peterson, 1980), and was used to measure caregiver burden. Item scores are summed to obtain a total score ranging 0-88, with higher scores indicating greater degree of burden or distress in the context of caregiver-patient relationship. The scores are classified as follows: 0–21 little or no burden, 21–40 mild to moderate burden, 41–60 moderate to severe burden, and 61–88 severe burden (Hérbert, Bravo, & Préville, 2000; Zarit, Reever, & Bach-Peterson, 1980). The Spanish version of the Zarit Burden Interview used in this study has good construct validity and internal reliability (α = .92) (Martin et al., 1996). The ZBI had a Cronbach's alpha in the present sample of α = 0.90.

2.2.2 Family Dynamics

Family Adaptability and Cohesion Evaluation Scale—Fourth Edition (FACES-IV)

The Spanish version of the FACES-IV (Rivero, Martínez-Pampliega, & Olson, 2010) was used to evaluate family satisfaction, communication, cohesion and flexibility. Two subscales measure balanced and unbalanced domains of flexibility (e.g., "It is important to follow the rules in our family") and cohesion (e.g., "Family members seem to avoid contact with each other when at home"). The subscales purport to measure the upper

and lower limits of cohesion (e.g., disengagement and enmeshment), and flexibility (e.g., rigid and chaotic). To evaluate these constructs, two ratio scores are created that measure the amount of balance versus unbalance within their respective domains, with higher scores (above the cutoff value of 1.0) representing more balanced or healthier systems (Olson, 2010). Additional two subscales provide measures of family communication and satisfaction (Family Communication Scale and Family Satisfaction Scale, respectively). The Spanish version of the FACES-IV has been validated, and shown to have adequate convergent, concurrent, and content validity as well as good internal consistency ($\alpha = .87$) (Rivero et al., 2010). Internal consistency in this sample ranged from $\alpha = 0.73$ on the subscales of cohesion and flexibility, to $\alpha = 0.95$ and $\alpha = 0.98$ for the scales of communication and satisfaction, respectively.

Relationship-Focused Coping Scale (RFCS)

The RFCS was utilized to evaluate empathic responding with an emphasis on preserving, managing, and/or maintaining relationships with family members during stressful periods (O'Brien & DeLongis, 1996). Participants were asked to endorse 10 items (e.g., "I tried to see things from the other person's point of view" and "I tried to understand how the other person felt") using a response scale from 0 (not at all) to 3 (a lot), with higher total scores representing greater levels of empathic responding. The RFCS has been validated and has shown good reliability and high internal consistency ($\alpha = .93$) (O'Brien & DeLongis, 1996). The translated version of this scale had excellent internal consistency ($\alpha = .92$) for this sample.

Family Assessment Device—General Functioning (FAD-GF)

The FAD-GF contains 12 items, measures overall health and dysfunction in the family system (Epstein, Baldwin, & Bishop, 1983), and is a useful tool for assessing family functioning in both clinical and research contexts (Mansfield, Keitner, & Dealy, 2014). Participants are asked to rate items (e.g., "Planning family activities is difficult because we misunderstand each other.") on a 4-point scale from 1 (strongly agree) to 4 (strongly disagree). Higher scores indicate more dysfunction and pathology within the family and more poor general functioning. The validated version of the FAD-GF has demonstrated good discriminant validity and good internal consistency ($\alpha = .83$) (Kabacoff, Miller, Bishop, Epstein, & Keitner, 1990). The FAD-GF in the present sample had good internal consistency ($\alpha = .86$).

2.2.3 Quality of Care Provision

The Exemplary Care Scale (ECS)

The ECS is composed of 11 items with response options provided on a Likert-type scale (1 = Never, 2 = Sometimes, 3 = Often, and 4 = Always). The ECS assesses two primary factors: (1) *Provision* of personalized care that extends beyond meeting basic needs (e.g. "I make sure the food my care recipient likes is available for meals and snacks"); and (2) *Respect* for the care recipient's feelings, wishes, opinions, self-esteem, and values (e.g., "I do everything I can to avoid making my care recipient feel that s/he is a burden to me") (Dooley et al., 2007). The scale was initially developed with samples of caregivers of older adults, and is a useful tool for evaluating quality of informal care for chronically ill people. Total scores range from 11-44, with higher scores indicating higher quality of care

provision (Dooley et al., 2007). Cronbach's alpha values for the *Provision* and *Respect* subscales of the ECS in this sample were $\alpha = 0.84$ and $\alpha = 0.91$, respectively.

2.3 Procedure

The study was reviewed and approved by the ethics committees of the University of Deusto (Spain), National Institute of Neurology and Neurosurgery (Mexico), and the Neurosciences Institute of San Lucas (Argentina). All participants received an explanation of the study and signed an informed consent form prior to enrollment. Subsequently, the participants completed a 60-90 minute interview with a psychologist, which took place during the care recipient's routine visit for a neurology consultation. During the interview the participants provided sociodemographic information and filled out the paper-and-pencil measures of family functioning and caregiver quality of care. The participants received no compensation for their participation.

2.4 Data Analysis

Using published clinical cutoffs for the measures of mental health, caregivers' scores on these measures were categorized and expressed as frequencies and percentages. Olson's (2010) scoring template was employed to calculate the ratio scores along the dimensions of flexibility and cohesion; raw communication and family satisfaction scores were used in the analyses.

All continuous variables in the study were tested for meeting the assumption of normal distribution by examining their skewness, kurtosis, and performing the Shapiro-

Wilk test of normality. Caregiver variables of months providing care (skewness = 1.850, *SE* = .213, kurtosis = 6.874, *SE* = .422; *S-W* = .870, *df* = 130, *p* = .009) and hours per week spent caregiving (skewness = 1.440, *SE* = .212, kurtosis = 2.316, *SE* = .422; *S-W* = .839, *df* = 130, *p* = .008), as well as mental health variables anxiety (skewness = 2.093, *SE* = .212, kurtosis = 4.883, *SE* = .424; *S-W* = .766, *df* = 130, *p* = .012), depression (skewness = 2.227, *SE* = .212, kurtosis = 4.528, *SE* = .422; *S-W* = .748, *df* = 130, *p* = .016), and family functioning variable of general family functioning (skewness = -1.527, *SE* = .212, kurtosis = 3.492, *SE* = .422; *S-W* = .869, *df* = 130, *p* = .009) were not normally distributed. Therefore, these variables were transformed using a square root transformation. Subsequently the results of Shapiro-Wilk test of normality for the transformed variables was no longer significant ($p > .05$), a relatively bell-shaped distribution was achieved in the histogram, as well as Q-Q plots with points adhering closely to the diagonal line, suggesting evidence of normality. Moreover, the boxplots did not reveal the presence of any potential outliers. These findings indicated that after the transformation the assumption of normality was met.

To check the assumptions of the multiple regressions, the residual plots of each model were generated and appropriate and normal distributions of residuals were observed. Additionally, skewness for the standardized residuals for each model was good (i.e., below 1.0). Presence of linear relationships was ascertained by performing curve estimation for all of the relationships in the statistical models. The obtained results determined that all of the relationships were sufficiently linear to be tested using multiple regression, as well as covariance-based structural equation modeling algorithm employed by AMOS. The absence of multicollinearity during multiple regression analyses was confirmed by examining the variance inflation factor (VIF) and tolerance values. Diagnostic criterion for

multicollinearity is when the VIF is above 10 (Tabachnick & Fidell, 2012). For all analyses, the VIF ranged from 1.173 to 2.759, indicating no multicollinearity problems. Another indicator of multicollinearity is when the tolerance statistic (calculated as 1 minus squared multiple correlation of each independent variable) is less than 0.10. In the present study the tolerance values for independent variables ranged from 0.225 (family communication) to 0.787 (empathy), which is greater than the 0.10 cutoff (Tabachnick & Fidell, 2012), providing further evidence of lack of multicollinearity in the multiple regression analyses. The dataset contained no missing values.

2.4.1 Objective 1

Participant scores on the measures of mental health and family functioning were expressed as means and percentages. Published cutoff values for clinical ranges were used to categorize participant responses for descriptive purposes. To examine bivariate relationships between caregiver sociodemographics (age, gender, and years of education), care variables (hours per week and total months providing care), patient cognitive status (MMSE score), and caregiver mental health (depression, anxiety, burden, and satisfaction with life), Pearson product-moment correlation was used. The relationship between caregiver burden and patient cognitive functioning was tested using ANOVA, with caregiver burden expressed as a factor with three levels (no/ little burden, mild-moderate burden, and moderate-severe burden), and MMSE score used as the dependent variable. Associations between categorical variables were examined using chi-square.

2.4.2 Objective 2

With the objective of assessing a pattern of relationships between caregivers' family dynamics and mental health, a canonical correlation analysis (CCA) model was constructed. The model used the ten observed/ measured variables to construct latent variables of mental health (burden, depression, anxiety, and satisfaction with life) and family dynamics (family cohesion, flexibility, communication, satisfaction, empathy, and general functioning). Canonical correlation is a comprehensive multivariate statistical procedure originally developed by Hotelling (1936). It allows for simultaneous comparison among the variables, and is most appropriate when examining the relationship between two sets of variables (Sherry & Henson, 2005). Among its advantages, canonical correlation limits the probability of committing Type I error anywhere within the study (Thompson, 1991). Additionally, this statistical approach is theoretically consistent with the research question at hand, as it does not merely examine singular causes and effects, but considers patterns of relationships with possible multiple causes and effects (Sherry & Henson, 2005). Finally, CCA as a statistical analysis technique is robust enough to detect stronger canonical correlations even with relatively small sample sizes (e.g., n = 50) (Barcikowski & Stevens, 1975).

Given its nature as a multivariate technique, canonical correlation forms functions which consist of weighted linear combinations (i.e., variates) of the independent and dependent variables. A typical canonical function is represented by the equation:

$$a_1Y_{1i} + a_2Y_{2i} + \cdots + a_pY_{pi} = b_1X_{1i} + b_2X_{2i} + \cdots + b_mX_{mi}$$

In the equation, X_{mi} represents an unspecified independent variable in the X-variate, and b_m represents the weight for that variable. On the other hand, Y_{pi} represents an unspecified dependent variable in the Y-variate, and a_p represents the weight for that variable. Weights are selected so as to maximize the canonical correlation between the variate representing the dependent variables and the variate representing the independent variables. The correlation between the Y and X variates is referred to as the canonical correlation.

Measures of family dynamics were considered to be independent variables and mental health measures were considered to be dependent variables. Wilks lambda (λ) was used to determine whether the canonical correlations were statistically significant. Standardized canonical coefficients were used to describe the variates that produced statistically significant canonical correlations, and squared canonical correlation was used to describe the amount of variance explained (analogous to the R^2 coefficient in multiple regression). SPSS macro "canonical correlation.sps" was used to execute the CCA.

Subsequently, in order to identify which family dynamics variables best predicted caregiver mental health while controlling for background and caregiver variables, a series of multiple regressions was performed. In each regression, caregiver and background variables which were significantly associated with the dependent variable in the correlation matrix (e.g., gender, age, education, months spent caregiving and hours per week spent providing care) were entered as independent variables in the first step, the six family dynamics variables were entered in the second step, and each of the four mental health variables were entered as the criterion variables in each regression.

2.4.3 Objective 3

Two hierarchical multiple regressions investigated the extent to which family dynamic variables (cohesion, flexibility, family satisfaction, family communication, general family functioning, and empathy) were associated with each of the caregiver quality of care variables (provision of exceptional care (Provide) and respect for care-recipient autonomy (Respect)), after controlling for demographics and caregiving characteristics. Each regression model was constructed using SPSS Linear Regression, Enter method, with caregiver gender, age, years of education, months spent caregiving, hours per week spent caregiving, and patients' score on the MMSE entered as variables in the first step, and the six family dynamic variables entered as independent variables in the second step. Each of the two caregiver quality of care variables were entered as the dependent variable in each regression. A significance level of 5% ($\alpha < 0.05$) was used for the analyses. Analyses were performed using SPSS 22.0 (IBM Corp, Armonk, NY).

2.4.4 Objective 4

In order to address the final study objective and evaluate the proposed theory-driven model of caregiver functioning, a structural equation model (SEM) was constructed using AMOS 22.0 (Arbuckle, 2007) for Windows. SEM is a statistical analysis procedure that incorporates elements of multiple regression, path analysis, and confirmatory factor analysis (Kline, 2010). One of its principal strengths is flexibility, which permits examination of complex associations, use of various types of data, and comparisons across alternative models (Wolf et al., 2013). SEM provides the opportunity to simultaneously measure latent and manifest variables directly and indirectly (Crockett, 2012; Kline, 2010).

Manifest variables are those which are directly observed, or measured in the study (e.g., patient's MMSE score), and are indicated as rectangles in Figure 1. Latent variables are constructs which are composed of observed variables and in the diagram are represented as ovals or circles. In the current study manifest variables of anxiety, depression, and satisfaction with life are combined to create a latent variable "Mental Health". One way arrows in the structural model represent directionality. For example, the arrow reaching from burden to Mental Health indicates that burden is predicting a relationship between itself and mental health. Single-headed arrows represent a hypothesized direct effect, and absence of a line indicates a lack of hypothesized direct effects.

The originally hypothesized model (Figure 3) included two manifest variables (1) care recipient cognitive functioning (MMSE score) and (2) caregiver burden (ZBI score), and four latent variables: (1) Background (caregiver age, hours per week providing care, and total months caregiving), (2) Mental Health (consisting of three observed variables: caregiver scores on the measures of depression, anxiety, and satisfaction with life), (3) Family Functioning (with six observed variables made of scores on the dimensions of cohesion, flexibility, family satisfaction and communication, empathy, and general functioning), and (4) Quality of Care (consisting of the scores on the two subscales of the Exemplary Care Scale). Direct effects, indicated by directional arrows in the model, were examined between variables to test hypotheses 1-4 of the final study objective, and mediational (indirect) effects of mental health were examined to address the final hypothesis via standardized beta weights among the variables in the model.

Determining sample size requirements for structural equation modeling (SEM) is a frequent challenge (Wolf et al., 2013). Power considerations in SEM requires sample sizes based on desired effect sizes, power level, number of latent variables, number of observed

variables, and probability level. Performing the SEM sample size calculations suggested by Lomax and Schumacker (2012) yielded a recommended minimum sample size of 100 participants to detect an anticipated medium effect size of 0.3 and a desired power level of 0.8 with four latent variables and 16 observed variables (Cohen, 1988; Soper, 2016; Westland, 2010). The available sample size of 130 participants exceeded the one recommended by the sample size calculator, and corresponded to or exceeded other recommended rules-of-thumb for sample calculation, such as a minimum of 100 (Boomsma, 1985), but was below the frequently recommended minimum of 200 (Kline, 2010). Other researchers had argued, however, that small samples suffice for SEM (Bentler, 1990; Bentler & Yuan, 1999; Westland, 2010). Jackson (2001, 2003) found only a small effect of sample size on model fit when he tested the hypothesis that an inadequate sample would result in poor-fitting models. Jackson's work suggests that the reliability of observed measures and the number of indicators per factor were more important determinants of model fit.

Model specification and identification steps of SEM occurred prior to data analysis. These steps included building hypothesized structural and measurement models to test the primary research hypothesis, as well as to ensure that the hypothesis can be tested by ensuring that the model is appropriately identified (Crockett, 2012; Kline, 2010). Model fit was assessed with maximum likelihood estimation, using multiple fit indices, including $\chi 2$, and ratio of $\chi 2$ to degrees of freedom, comparative fit index (CFI), Tucker-Lewis index (TLI), Bentler-Bonett Index/ Normed Fit Index (NFI), and root mean square error of approximation (RMSEA). The fit indices chosen represent both incremental fit indices (e.g., CFI and TLI), which indicate how good a model fits the data, and absolute fit indices (e.g., RMSEA), which measure how poor a model is (Kenny, 2015). Larger values (greater

than 0.9) for incremental fit indices and smaller values for absolute fit indices (below 0.08) indicate good model fit.

3 Results

3.1 Objective 1

Caregiver Mental Health Functioning

Categorization of the scores on the Zarit Burden Interview according to the published criteria (Zarit, Reever, & Bach-Peterson, 1980) revealed that approximately one fifth of participants reported experiencing little or no burden (20.8%), while 79.2% of the caregivers experienced clinically significant burden. Of these, 1.5% reported severe burden, 29.2% moderate-to-severe burden, and 48.5% mild-to-moderate burden. Further analysis of participants' responses revealed that the most frequent symptoms of burden, endorsed by the vast majority of caregivers, was feeling that the loved one with dementia is dependent upon the caregiver (endorsed by 94.6% of caregivers), being fearful of what the future holds for the PwD (92.3%), not having enough time for themselves (91.5%), feeling stressed between providing care and trying to meet other family or work responsibilities (90.8%), and feeling that the care recipient seems to expect to be taken care of (90%). Additionally, 81.5% expressed feeling overall burdened in caring for their relative, 50.8% of caregivers agreed that their social life has suffered because of their caregiving duties, and 49.2% indicated that their relative with dementia affected the caregiver's relationship with other family members. The least frequently endorsed burden symptoms were feeling angry around the care recipient (endorsed by 29.2% of participants), feeling uncomfortable having friends over because of the PwD (19.2%), and feeling embarrassed about their relative's behavior (18.5%).

Based on the cutoffs established by the authors of the Patient Health Questionnaire-9 (Kroenke, Spitzer, & Williams, 2001), 26.9% of the caregivers were experiencing

clinically significant levels of depression, with 18.5% reporting mild depression, 4.6% moderate depression, and 3.8% moderate-severe depression, while 73.1% were not considered clinically depressed. The most frequently endorsed symptoms of depression were trouble falling asleep, staying asleep, or sleeping too much (endorsed by 70% of caregivers), feeling tired or having little energy (66.9%), and feeling down, depressed or hopeless (40%); 5.4% of caregivers indicated having had thoughts of being better off dead or of hurting themselves in some way. Further, 22.3% of participants indicated that their depressive symptoms made it difficult for them to do their work, take care of things at home, or get along with other people.

Using the Spitzer et al. (2006) cut off points for classifying anxiety, 3.1% of participants obtained scores consistent with severe levels of anxiety, 5.4% moderate, 17.7% mild anxiety, while 73.8% indicated no clinical levels of anxiety. The most frequently endorsed symptoms were trouble relaxing (endorsed by 77.7% of caregivers), followed by feeling nervous, anxious, or on edge (56.2%), worrying too much about different things (53.1%), and not being able to stop or control worrying (50%).

Classification of Satisfaction with Life Scale (Pavot & Diener, 1995) yielded the following results: 9.2% of caregivers were classified as being dissatisfied with life, 17.7% as slightly dissatisfied, 6.2% as neutral, 41.5% as slightly satisfied, 19.2% as satisfied, and 6.2% as extremely satisfied. The average SWLS score for the sample was 4.52 (SD = 1.2), indicating overall neutral satisfaction with life (Pavot & Diener, 2008).

Means, standard deviations, and ranges for scores on measures of depression, anxiety, burden, and satisfaction with life are presented in Table 2.

Table 2. Scores on measures of mental health functioning.

Variable	Mean	SD	Range
Depression (PHQ-9)	3.82	4.38	0-23
Anxiety (GAD-7)	3.98	4.11	0-21
Burden (ZBI)	32.33	12.89	5-63
Satisfaction with Life (SWLS)	22.6	5.98	10-35

Caregiver Family Functioning

Classification of participants' responses on the Family Satisfaction Scale according to Olson's (2010) criteria, 42.3% of caregivers endorsed having very low satisfaction with family functioning, 19.2% low satisfaction, 5.4% moderate, 23.8% high satisfaction, and 9.2% very high family satisfaction. On the Family Communication Scale, 26.9% indicated very low score on the dimension of family communication, 13.8% low communication, 22.3% moderate, 26.9% high, and 10% very high family communication score, indicating better functioning in this domain.

The FACES-IV scoring algorithm (Olson, 2010) generates balanced score classifications for flexibility and cohesion, which are used for clinical and descriptive purposes, and recommend the use of cohesion ratio and flexibility ratio scores for research (the values above 1.0 indicate an equal amount of balance versus unbalance in the system). On the family functioning domain of flexibility, the majority of participants (80%, n=104) indicated that their family functioning is flexible according to their balanced scale percentage score, while 12% categorized it as somewhat flexible, and the remaining 8% as very flexible. A similar pattern was observed in regards to the caregivers' scores on the cohesion domain of FACES-IV. The vast majority (64%) responded that their family is connected, 12% indicated their family functioning as somewhat connected, and 25% as very connected. This classification permits creation of a conceptual overlap between the two constructs (Table 3). Families who score highly on cohesion and flexibility are referred to as "flexibly connected" and in the current sample included 8% of the participants. Families with low cohesion and low flexibility are thought to represent "structurally separated" units (5% of caregivers). High cohesion with low flexibility represents a

structurally connected family, while low cohesion and high flexibility tends to describe structurally connected family units; no caregivers fell into these classification ranges. The majority, 80% of participants, indicated that their family functioning was in the balanced range on cohesion and flexibility.

Table 3. Classification on family cohesion and flexibility.

		Cohesion		
		Low	Balanced	High
Flexibility	High	0%	1%	8%
	Balanced	6%	57%	17%
	Low	5%	6%	0%

On the FAD-GF, a measure of general family functioning and pathology in the family unit, caregivers' scores ranged from 1 to 3.25. The majority of participants, 87.7% (n=114) obtained a score above the cutoff value of 2.0 (Epstein et al., 1983; Miller, Ryan, Keitner, Bishop & Epstein, 2000), indicating relatively poor overall family functioning in the majority of the caregivers families. Means and standard deviations for caregivers' cohesion ratio and flexibility ratio scores, raw communication and satisfaction scores on the FACES-IV, as well as scores on measures of empathy and general functioning are presented in Table 4.

Table 4. Scores on measures of family dynamics.

Variable	Mean	SD
Cohesion Ratio	2.37	1.17
Flexibility Ratio	1.78	0.67
Family Communication	34.84	8.15
Family Satisfaction	31.0	10.04
Empathy	20.26	5.37
General Functioning	2.40	0.38

Relationship between Caregiver Sociodemographics and Mental Health

A correlation matrix was generated to examine bivariate relationships among sociodemographic variables (age, gender, and years of education), care provision/ context variables (total months and hours per week providing care), patient cognitive functioning/ objective stressor variable (MMSE score), and caregiver mental health variables in the current study (Table 5). Higher caregiver age was significantly correlated with more total months providing care and hours spent caregiving per week, and negatively correlated with years of education and gender. Lower patient MMSE score was significantly associated with longer duration (in months) and greater time investment per week of providing care by the family member. Of the three sociodemographic variables, gender was negatively correlated with burden, and education negatively correlated with anxiety and depression. This indicates that participants with lower education tended to experience higher levels of anxiety and depression, and male caregivers tended to have higher subjective burden. Caregiver age was not correlated with any mental health variable.

Table 5. Correlations between sociodemographic, care provision, and mental health variables.

Variable	1	2	3	4	5	6	7	8	9	10
1.Age	1									
2.Gender	-.19*	1								
3.Education	-.32**	-.16	1							
4.Time CG (months)	.23**	-.23**	.05	1						
5.Hrs/ week CG	.23**	-.05	-.39**	.17	1					
6.MMSE	.06	.14	.03	-.39**	-.26**	1				
7.Depression	.16	-.09	-.24**	-.09	.26**	-.27**	1			
8.Anxiety	.08	.06	-.19*	.07	.31**	-.26**	.53**	1		
9.Burden	.08	-.20*	-.05	.26**	.18*	-.29**	.42**	.52**	1	
10.Satisfaction with Life	.05	.14	.04	-.23**	-.05	-.11	-.18*	-.15	-.44**	1

*$p \leq .05$. **$p \leq .01$.

More total months spent providing care was significantly associated with higher caregiver burden, lower satisfaction with life, and was not correlated with depression or anxiety. More hours per week spent providing care was significantly correlated with higher burden, anxiety, and depression, but not correlated with satisfaction with life. Additionally, lower patient cognitive functioning was significantly associated with higher caregiver depression, anxiety, and burden, but not satisfaction with life, providing partial support to the study hypotheses 1A and 1B. All mental health variables showed significant association among themselves, except for anxiety and satisfaction with life, which were not significantly correlated.

3.2 Objective 2

Family Dynamics and Mental Health

In order to address the study objective of examining the relationship between caregiver family functioning and mental health, a canonical correlation analysis was conducted using the six family dynamics variables (cohesion, flexibility, satisfaction, communication, general functioning, and empathy) as predictors of the four mental health variables (depression, anxiety, burden, and satisfaction with life) to evaluate the multivariate shared relationship between the two variables sets (i.e., family dynamics and mental health). CCA yields a number of canonical correlations equal to a number of variables in the smallest variable set; in the present study, the caregiver mental health variable set contained four variables. Therefore, the canonical correlation analysis produced four canonical correlations, each made up of unique patterns of shared variance between the two variable sets. In CCA the first canonical correlation is always the largest, with each additional canonical correlation decreasing in magnitude. Figure 4 depicts the conceptual basis for this study objective, and the result of the first canonical correlation. Latent variables of family dynamics and mental health are depicted as circles, connected to their respective observed variables.

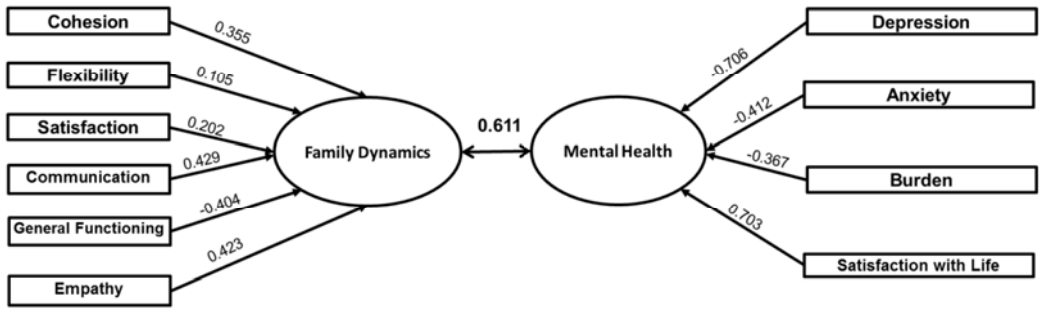

Figure 4. Canonical correlation model and standardized coefficients.

The first canonical correlation was 0.611 (37.3% overlapping variance), with a Wilks's λ =.537, $\chi^2(24) = 76.830$, $p < .001$, a large-sized effect according to Cohen's standards (Cohen, 1988). The second, third, and fourth canonical correlations were 0.347 (12% shared variance; Wilk's λ =.856, $\chi^2(15) = 19.206$, $p = .205$), 0.160 (2.56% shared variance; λ =.973, $\chi^2(8) = 3.375$, $p = .909$), and 0.036 (less than 1% shared variance; λ =.999, $\chi^2(3) = 0.160$, $p = .984$), respectively. As none of them were statistically significant, they were not interpreted.

Standardized canonical coefficients were used to examine the relative contribution of each variable to the overall canonical correlation. In the first canonical correlation, the standardized canonical coefficients for the caregiver family dynamics variables showed that family communication loaded most highly (0.429), followed in magnitude by empathy (0.423), general family functioning/ pathology (-0.404), and family cohesion (0.355). Because the coefficients reflecting communication, empathy, and general functioning were above the conventional cutoff of 0.4 (Tabachnick & Fidell, 2012), these were focused on for interpretation. For the mental health variables, depression loaded most highly (-0.706), followed by satisfaction with life (0.703), and anxiety (-0.412); all other coefficients were below 0.4.

Overall, these results support the hypothesis that a significant relationship exists between caregiver family and mental health functioning. The observed pattern of shared variance suggests that caregivers of individuals with dementia experience lower levels of burden and depression, as well as higher satisfaction with life when their family unit exhibits higher levels of family communication and empathy, and lower overall family pathology.

To fine-tune the results obtained by the canonical correlation analysis, a set of hierarchical multiple regressions was employed to further investigate which family dynamics variables were most related to the four caregiver mental health variables while controlling for sociodemographic and caregiving variables.

Depression

In the first hierarchical multiple regression with depression as the criterion variable (Table 6), those caregiver demographic and caregiving characteristics which were shown to correlate with this dependent variable (i.e., education, hours per week providing care, and patient's MMSE score) were entered into the first step. The first model was statistically significant, $F(3, 129) = 6.225$, $p = 0.001$, $R^2 = 0.109$. The second model, which included the six family dynamics variables in the second step, was significant, $F(9, 129) = 3.276$, $p = .001$, $R^2 = 0.197$, and the amount of variance explained in caregiver depression increased by a significant $\Delta R^2 = 0.088$, $\Delta F(6, 120) = 2.698$, $p = 0.013$. The final model explained nearly 20% of the variance, which corresponds to Cohen's $f^2 = .245$, indicating medium effect size (Cohen, 1988; Soper, 2016). Caregivers' general family functioning $\beta = 0.192$, $t(129) = 2.172$, $p = 0.032$, and family cohesion, $\beta = -0.293$, $t(129) = -2.083$, $p = 0.039$, as well as patient MMSE score, $\beta = -0.200$, $t(129) = -2.352$, $p = 0.020$, were significantly and independently associated with caregiver depression. This pattern of findings indicates that caregivers with better overall family functioning and higher family cohesion, and better patient cognitive functioning may experience lower levels of depression.

Table 6. Summary of hierarchical multiple regression analysis for caregiver and family dynamics variables predicting depression.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Education	-0.04	0.02	-0.17	-0.05	0.02	-0.20
Hours/ week Caregiving	0.08	0.05	0.16	0.06	0.05	0.12
MMSE Score	-0.07	0.03	-0.20*	-0.07	0.03	-0.19*
Cohesion				0.28	0.13	-0.29*
Flexibility				-0.19	0.21	-0.11
Satisfaction				-0.01	0.02	-0.09
Communication				-0.02	0.02	-0.13
Gen. Functioning				1.60	0.74	0.19*
Empathy				0.01	0.02	0.03
R^2		0.11			0.20	
ΔR^2		0.11			0.09	
F for change in R^2		6.23**			2.70*	

*$p < .05$.

Anxiety

The second hierarchical multiple regression was performed in the same manner but substituting caregiver anxiety as criterion variable (Table 7). The first model was statistically significant, F(3, 129) = 6.138, p = 0.001, $R^2 = 0.128$, as well as the second model, which included the six family dynamics variables in the second step, F(9, 129) = 3.735, p < 0.001, $R^2 = 0.219$. The amount of variance explained in caregiver anxiety increased by a significant $\Delta R^2 = 0.091$, ΔF(6, 120) = 2.338, p = 0.036. The final model helped explain 21.9% of the variance (Cohen's $f^2 = .280$, indicating medium effect size), and revealed that caregivers' general family functioning $\beta = 0.230$, $t(129) = 2.342$, $p = 0.023$ was independently predictive of caregiver anxiety. Additionally, caregiver variable of hours per week providing care, β = 0.247, t(129) = 2.709, p = 0.008, emerged as significantly associated with caregiver anxiety, indicating that caregivers tended to

experience higher levels of anxiety if they had a greater caregiving load per week and experienced overall worse patterns of general family functioning. Additionally, patient MMSE score approached significance in predicting caregiver anxiety, β = -0.170, t(129) = -1.988, p = 0.05, suggesting that lower patient cognitive functioning may also be predictive of higher levels of caregiver anxiety.

Table 7. Summary of hierarchical multiple regression analysis for caregiver and family dynamics variables predicting anxiety.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Education	-0.02	0.02	-0.09	-0.02	0.02	-0.10
Hours/ week Caregiving	0.11	0.04	0.23*	0.12	0.05	0.25**
MMSE Score	-0.06	0.03	-0.17*	-0.06	0.03	-0.17
Cohesion				0.05	0.12	0.06
Flexibility				-0.19	0.19	-0.12
Satisfaction				-0.01	0.02	-0.14
Communication				-0.02	0.02	-0.13
Gen. Functioning				1.23	0.37	0.23*
Empathy				-0.01	0.01	-0.02
R^2		0.13			0.22	
ΔR^2		0.13			0.09	
F for change in R^2		6.14**			2.34*	

*$p < .05$. **$p < .01$.

Burden

The third hierarchical multiple regression was run in the same manner but with caregiver burden as the criterion variable (Table 8). The first model, which controlled for caregiver variables of gender, months spent providing care and hours caregiving per week, along with patient MMSE score, was statistically significant, $F(4, 129) = 4.793$, $p = 0.001$, R^2=0.133. The second model was also significant, $F(10, 129) = 4.419$, $p < 0.001$,

R^2=0.271, accounting for 27% of the variance explained, Cohen's f^2 = .372 (indicating large effect size; Cohen, 1988). The statistically significant independent predictor of caregiver burden in the second model was patient MMSE score, β = -0.240, t(129) = -2.579, p = 0.011, with hours spent providing care approaching significance, β = 0.150, t(129) = 1.821, p = 0.071. No other independent variables were significantly associated with the criterion variable of caregiver burden (all *p*s > .168), indicating that lower patient cognitive functioning was the best predictor of higher caregiver burden in the current sample.

Table 8. Summary of hierarchical multiple regression analysis for caregiver and family dynamics variables predicting burden.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Gender	-4.12	2.58	-0.14	-3.08	2.48	-0.10
Months Caregiving	0.96	0.56	0.16	0.61	0.54	0.10
Hours/ week Caregiving	0.66	0.53	0.11	0.93	0.51	0.15
MMSE Score	-0.74	0.38	-0.18*	-1.01	0.39	-0.24*
Cohesion				0.43	1.49	0.04
Flexibility				-3.22	2.32	-0.17
Satisfaction				-0.13	0.19	-0.09
Communication				-0.22	0.26	-0.14
Gen. Functioning				-9.93	8.39	-0.10
Empathy				-0.24	0.21	-0.10
R^2		0.13			0.27	
ΔR^2		0.13			0.14	
F for change in R^2		4.79**			3.75**	

*$p < .05$. **$p < .01$.

Satisfaction with Life

The final hierarchical multiple regression examined the relationship between the six family dynamic variables and caregiver SWL after controlling for caregiver characteristic of months providing care (Table 9). The first model was statistically significant, $F(1, 129) = 7.176$, $p = 0.008$, $R^2 = 0.053$. The second model was also significant, $F(7, 129) = 6.985$, $p < 0.001$, R^2=0.286, and the amount of variance explained in caregiver satisfaction with life increased by a significant $\Delta R^2 = 0.233$, ΔF(6, 121) = 6.637, p < 0.001. Caregiver family empathy, $\beta = 0.243$, $t(129) = 2.897$, $p = 0.004$ was significantly associated with caregiver life satisfaction. Additionally, caregiver variable of time providing care (in months), β = -0.169, $t(129) = -2.163$, $p = 0.032$ emerged as a significant predictor of caregiver satisfaction with life. Family communication was marginally significant, $\beta = 0.276$, $t(129) = 1.728$, $p = 0.086$. These results indicate that higher levels of family empathy, together with fewer months providing care are associated with higher general satisfaction with life in the current sample of family caregivers.

Table 9. Summary of hierarchical multiple regression analysis for caregiver and family dynamics variables predicting satisfaction with life.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Months Caregiving	-0.66	0.25	-.23**	-0.49	0.22	-0.17*
Cohesion				0.35	0.66	0.07
Flexibility				-0.10	1.04	-0.01
Satisfaction				-0.03	0.09	-0.01
Communication				0.20	0.12	0.28
Gen. Functioning				-4.66	3.52	-0.10
Empathy				0.27	0.09	0.23**
R^2		0.05			0.29	
ΔR^2		0.05			0.23	
F for change in R^2		7.18**			6.64***	

*$p < .05$. **$p < .01$. ***$p < .001$.

3.3 Objective 3

Family Dynamics and Quality of Care Provision

A correlation matrix was generated to examine the bivariate relationships between caregiver family dynamics and quality of care in the current study (Table 10). Caregiver exemplary care provision variables (Provide and Respect) were positively and significantly correlated. Caregiver quality of care (Provide) was positively correlated with empathy, cohesion, communication, and family satisfaction, was negatively related to general family functioning/ pathology, and approached significance in its correlation with flexibility ($p = .062$). Caregiver quality of care (Respect) was positively correlated with empathy, cohesion, flexibility, communication, and family satisfaction, and negatively correlated with general family functioning. All family dynamic variables were significantly related to each other.

Table 10. Correlations between caregiver family dynamics and quality of care.

Variables	1	2	3	4	5	6	7	8
1. Gen. Functioning	1							
2. Cohesion	-.66**	1						
3. Flexibility	-.54**	.81**	1					
4. Satisfaction	-.74**	.57**	.43**	1				
5.Communication	-.76**	.63**	.55**	.78**	1			
6.Empathy	-.24**	.31**	.22*	.29**	.37**	1		
7.Care-Provide	-.31**	.25**	.16	.29**	.28**	.38**	1	
8.Care-Respect	-.34**	.23**	.19*	.31**	.33**	.44**	.88**	1

*$p \leq .05$ (2-tailed). **$p \leq .01$ (2-tailed).

Quality of Care-Provide

The relationship between family dynamics and quality of care variables were investigated using hierarchical multiple regression. In the first hierarchical multiple regression model (Table 11), the caregiver characteristics (caregiver age, gender, years of education, months spent caregiving, and hours per week spent caregiving) and patient's MMSE score were entered into the first step. The first model was significant, $F(7, 129) = 2.395$, $p = .026$, with an $R^2 = .133$. The second model including the six family dynamic variables was also significant, indicating that the predictors accounted for around 28% of the variance, $F(13, 129) = 3.034$, $p = .001$, $R^2 = .277$. The obtained value of R^2 corresponds to Cohen's $f^2 = .383$, indicating large effect size (Cohen, 1988; Soper, 2016).

When the caregiver quality of care variable was regressed onto the family dynamics variables, the amount of variance explained in caregiver quality of care increased by a significant $\Delta R^2 = .144$, $\Delta F(6, 117) = 3.409$, $p = .004$. Months providing care was significantly related to Provide, $\beta = -.253$, $t(129) = -2.492$, $p = .014$, such that longer duration of care provision was associated with lower levels of Quality of Care-Provide. Additionally, family dynamics variables of empathy ($\beta = .268$, $t(129) = 2.836$, $p = .005$) and general functioning ($\beta = .-521$, $t(129) = -2.132$, $p = .021$) were significantly associated with Quality of Care-Provide, with higher levels of empathy and better general functioning linked with greater levels of Quality of Care-Provide. However, cohesion, communication, family satisfaction, and flexibility were not independently related to Quality of Care-Provide (all $ps > .565$).

Table 11. Summary of hierarchical multiple regression analysis for caregiver and family dynamics variables predicting quality of care-Provide.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Mini-mental Score	-0.10	0.08	-0.14	-0.13	0.08	-0.19
Months Caregiving	-0.03	0.10	-0.27*	-0.03	0.10	-0.25*
Hours/ week Caregiving	-0.01	0.01	-0.02	-0.01	0.01	-0.02
Age	0.01	0.02	0.04	0.02	0.02	0.09
Gender	0.28	0.52	0.05	0.16	0.50	0.03
Education	-0.14	0.06	-0.28	-0.11	0.06	-0.23
Empathy				0.12	0.04	0.27**
Gen. Functioning				-2.34	0.83	-0.52*
Cohesion				0.21	0.32	0.10
Flexibility				-0.19	0.51	-0.05
Communication				-0.01	0.05	-0.02
Fam. Satisfaction				0.02	0.04	0.09
R^2		.13			.28	
ΔR^2		.13			.14	
F for change in R^2		2.40*			3.41**	

*$p < .05$. **$p < .01$.

Quality of Care-Respect

The second hierarchical multiple regression model was run in the same manner as the first, but substituting caregiver Quality of Care-Respect as the dependent variable (Table 12). The first model was not significant, $F(7, 129) = 1.550$, $p = .158$, $R^2 = .091$. When the caregiver Quality of Care-Respect scores were regressed onto the six family dynamics variables, the second model was significant, $F(13, 129) = 3.442$, $p < .001$, $R^2 = .303$, with the amount of variance explained in caregiver Respect increasing significantly, $\Delta R^2 = .212$, $\Delta F(6, 117) = 5.228$, $p < .001$.

Empathy was significantly associated with Respect, $\beta = .364$, $t(129) = 3.928$, $p = .001$, as was general functioning, $\beta = .-420$, $t(129) = -2.543$, $p = .005$, such that higher levels of empathy and better general functioning were associated with greater levels of

Quality of Care-Respect. These two variables explained 30% of the variance, which corresponds to Cohen's f^2 = .435, indicating large effect size (Cohen, 1988; Soper, 2016). None of the other family dynamics variables were independently related to Quality of Care: Respect (all *p*s > .304).

Table 12. Summary of hierarchical multiple regression analysis for caregiver and family dynamics variables predicting quality of care–Respect.

	Model 1			Model 2		
Variable	*B*	*SE B*	*β*	*B*	*SE B*	*β*
Mini-mental Score	-0.21	0.15	-.16	-0.21	0.15	-.16
Months Caregiving	-0.04	0.02	-.22	-0.04	0.02	-.20
Hours/ week Caregiving	-0.01	0.02	-.04	-0.01	0.02	-.05
Age	0.01	0.04	.02	0.04	0.03	.12
Gender	0.22	0.98	.02	0.53	0.91	.01
Education	-0.23	0.11	-.16	-0.15	0.11	-.17
Empathy				0.30	0.08	.36**
Gen. Functioning				-4.28	1.55	-.42**
Cohesion				-0.29	0.58	-.08
Flexibility				0.54	0.93	.08
Communication				0.04	0.09	.07
Fam. Satisfaction				0.04	0.07	.09
R^2		.09			.30	
ΔR^2		.09			.21***	
F for change in R^2		1.55**			5.23***	

Note: *$p < .05$. **$p < .01$. ***$p < .001$.

3.4 Objective 4

Theoretical Model Testing

A model constructed with AMOS 22.0 (Arbuckle, 2007) was utilized to test the predicted pattern of relationships between manifest and latent variables. A direct effect of lower patient cognitive functioning and higher indicators of caregiver care variables (older age, higher total months and hours per week providing care) on greater caregiver burden was hypothesized. Further, caregiver burden was predicted to have an inverse direct effect on both mental health and family dynamics. These two latent constructs were hypothesized to have a direct, significant effect on quality of care provision. Finally, it was hypothesized that mental health would have a mediating effect on relationship between family dynamics and quality of care (Figure 3).

When the SEM analysis of the hypothesized model was conducted, the evaluation of model fit parameters indicated poor fit, $\chi^2(99) = 309.239$, $p<.0001$, CFI = 0.753, TLI = 0.701, NFI = 0.682 (values higher than .90 indicate adequate fit), and RMSEA = 0.128 (value of .08 or less indicates a better fitting model) (Byrne, 2009; Hu & Bentler, 1999). Examination of model estimates revealed that the path leading from Background to Burden failed to reach significance, $\beta = 0.160$, $p = .148$, while all other hypothesized connections were significant (Table 13). This indicates that the manifest variables of the latent construct "Background" do not provide a sufficiently strong contribution to the overall theorized model. Additionally, standardized regression weight for quality of care-Respect was 1.011, which exceeded the value of 1.0. This occurrence indicates the presence of negative variance estimate, also referred to as Heywood case (Kolenikov & Bollen, 2012). While a

fairly common issue in SEM, there is not a singular causal factor of Heywood cases. Its presence has been attributed to missing data (Wothke, 1993),

Table 13. Standardized and unstandardized estimates, standard errors, and significance values for Model 1.

Path Destination		Path Origin	B	S.E.	β	p
Burden	<---	Pt. Cog Function	-1.838	.416	-.386	< .001
Burden	<---	Background	.177	.122	.160	.148
Family Functioning	<---	Burden	-.214	.069	-.299	.002
Mental Health	<---	Burden	-.184	.035	-.684	< .001
MH	<---	Family Functioning	.099	.040	.264	.014
Quality of Care	<---	Mental Health	.457	.170	.342	.007
Quality of Care	<---	Family Functioning	.087	.054	.373	.010
Depression	<---	Mental Health	-.165	.036	-.588	< .001
Anxiety	<---	Mental Health	-.163	.034	-.629	< .001
Satisfaction with Life	<---	Mental Health	1.000		.590	
Care-Provide	<---	Quality of Care	.474	.056	.883	< .001
Care-Respect	<---	Quality of Care	1.000		1.011	
Satisfaction	<---	Family Functioning	1.000		.876	
Flexibility	<---	Family Functioning	.039	.006	.539	< .001
Cohesion	<---	Family Functioning	.091	.011	.676	< .001
Empathy	<---	Family Functioning	.207	.056	.353	< .001
General Functioning	<---	Family Functioning	.005	.001	-.621	< .001
Communication	<---	Family Functioning	.872	.066	.951	< .001
Age	<---	Background	1.000		.820	
Months Caregiving	<---	Background	.042	.021	.268	.042
Hours/ week Caregiving	<---	Background	.076	.030	.669	.013

sampling fluctuations (Anderson and Gerbing, 1984), and outliers (Bollen, 1987). Since the data in the current study did not contain these errors, the presence of the Heywood case was attributed to high correlation between the two manifest variables of the latent construct "Quality of Care", which likely resulted in negative variance estimation and exceedingly high value of the standardized regression weight.

In light of these findings, the hypothesized structural model was re-specified as follows. The latent variable "Background" (and its subordinate connections) was removed from the model in order to account for lack of significance in its impact on "Burden". The presence of the Heywood case was addressed by substituting the latent variable "Quality of Care" with the observed variable of the same name. The observed variable "Quality of Care", indicated as a rectangle in Figure 5, corresponded to the participants' total score on the Exemplary Care Scale, and was used as the measure of final outcome in the model (Model 2) instead of the two subscales. Model 2 also tested the hypothesis that continued evidence of the Heywood case on the manifest variable Quality of Care in Model 2 would indicate model specification error. After these re-specifications the model was re-run, and obtained fit indices were evaluated.

Fit indices for Models 1 and 2 are presented in Table 14. The re-specified, second model resulted in substantially improved fit indices: $\chi^2(99) = 50.067$, p=.05, CFI = 0.971, TLI = 0.946, NFI = 0.915, and RMSEA = 0.063. No negative variance estimation (i.e., Heywood case) was present. The obtained values indicated good model fit, and estimated standardized path coefficients revealed the predicted directionality and significance (Table 15), providing strong support to the hypotheses theorized in the final objective of the study.

Table 14. Comparison of the fit indices.

	$\chi 2$	df	p	$\chi 2$/df	CFI	TLI	NFI	RMSEA
Model 1	309.239	99	<.0001	3.12	0.753	0.701	0.682	0.128
Model 2	50.067	35	0.05	1.43	0.971	0.946	0.915	0.063

More specifically, patient cognitive functioning, as measured by the MMSE score, positively associated with caregiver burden, $\beta = -0.392$, $p < 0.001$. Caregiver burden, in turn, was positively associated with both mental health, $\beta = -0.574$, $p < 0.001$ and family functioning, $\beta = -0.271$, $p = 0.006$. Family functioning positively directly impacted on quality of care, $\beta = 0.324$, $p = 0.01$, and mental health functioning, $\beta = 0.304$, $p = 0.003$, as well as indirectly on quality of care via mental health, $\beta = 0.283$, $p = 0.020$, indicating mediational effect of mental health in the context of the model. The highest standardized coefficients emanating from the latent variables were all significant, with the highest value of coefficients from mental health were directed towards anxiety ($\beta = -0.73$) and satisfaction with life ($\beta = 0.72$), while for family functioning they were directed to empathy ($\beta = 0.79$), family satisfaction and communication ($\beta = 0.76$ for each), and general functioning ($\beta = -0.75$) (Table 15).

Taken all together, these results indicate strong support for the hypothesized relationships and directionality between latent and manifest variables in the theory-driven model grounded in Pearlin's (1990) Stress Process Model and structural family theory. Good fit indices which were obtained in fitting Model 2 to the data suggest that patient's cognitive functioning accounts for greater variance in caregiver burden than background variables (age, time spent caregiving in total and per week), and high quality of family-

based care provision, as measured by the Exemplary Care Scale, is best captured by the total scale score, and is likely a unitary construct in the context of the current sample of dementia caregivers from Latin America. Healthier family functioning overall, and particularly higher empathy, and stronger family communication and satisfaction, as well as higher satisfaction with life are strongly predictive of high quality of person centered, family based, exemplary care provision by caregivers of individuals with dementia in the current sample.

Table 15. Standardized and unstandardized estimates, standard errors, and significance values for Model 2.

Path Destination		Path Origin	B	S.E.	β	p
Burden	<---	Pt. Cog Function	-1.872	.421	-.392	< .001
Family Functioning	<---	Burden	-.167	.061	-.271	.006
Mental Health	<---	Burden	-.188	.034	-.574	< .001
Mental Health	<---	Family Functioning	.163	.055	.304	.003
Depression	<---	Mental Health	-.134	.030	-.583	< .001
Anxiety	<---	Mental Health	-.154	.034	-.725	< .001
Satisfaction with Life	<---	Mental Health	1.000		.722	
Satisfaction	<---	Family Functioning	1.000		.756	
Flexibility	<---	Family Functioning	.033	.013	.400	.012
Cohesion	<---	Family Functioning	.095	.023	.606	< .001
Empathy	<---	Family Functioning	.536	.150	.789	< .001
General Functioning	<---	Family Functioning	.007	.002	-.750	< .001
Communication	<---	Family Functioning	.808	.073	.761	< .001
Quality of Care	<---	Mental Health	.459	.253	.283	.020
Quality of Care	<---	Family Functioning	.280	.109	.324	.010

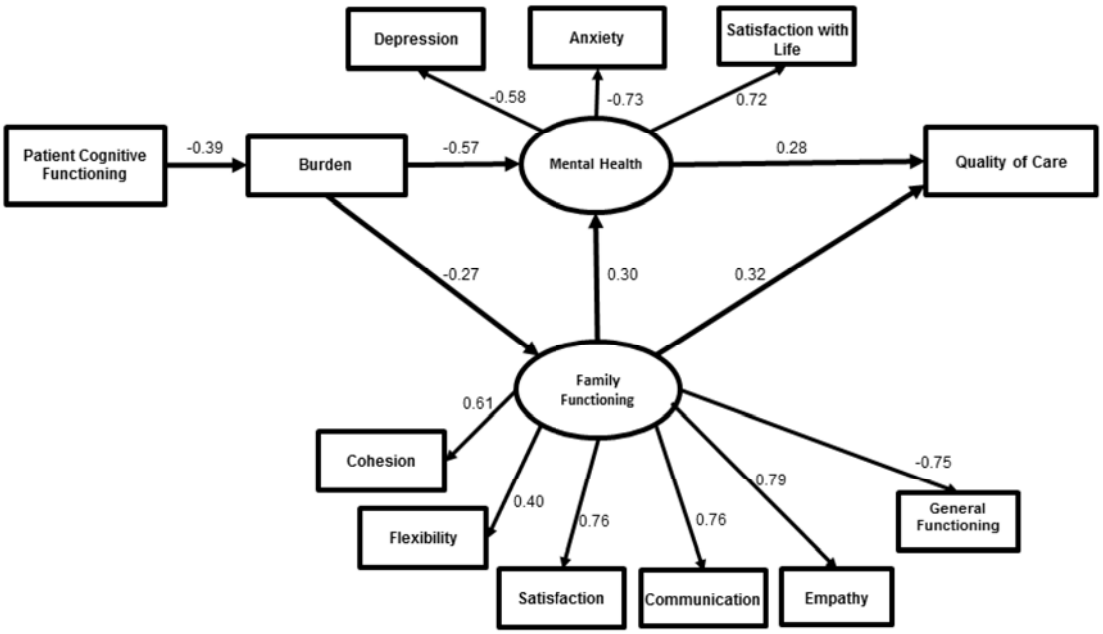

Figure 5. Final model and standardized path coefficients.

4 Discussion

4.1 Sociodemographic, Care Provision, and Mental Health Variables

The first objective of the study was to describe principal sociodemographic, care provision, and mental health functioning variables of family caregivers of individuals with dementia in Latin America who made up the current sample. It was hypothesized that a significant inverse relationship would exist, such that higher caregiving load, evidenced by longer duration of care provision overall and in hours per week, would be significantly associated with worse mental health functioning (i.e., higher scores on the measures of depression, anxiety, and burden, and lower satisfaction with life). Additionally, lower patient cognitive functioning, as measured by the MMSE score, was hypothesized to be significantly associated with higher caregiver burden and worse mental health functioning.

Based on the results of correlation analysis these hypotheses received partial support. More specifically, only one mental health variable (burden) was significantly correlated with both hours per week spent caregiving and total (in months) duration of providing care. Hours per week showed significant inverse association with life satisfaction, while longer months spent providing care was strongly associated with higher indices of depression and anxiety, but not satisfaction with life. Similarly, lower patient cognitive functioning was significantly associated with worse anxiety, depression, and burden (in order of increasing magnitude indicated by the correlation coefficient), but not life satisfaction.

The lack of full support for the hypotheses indicated by the absence of a significant negative association between caregiver satisfaction with life and patient cognitive functioning or weekly time spent providing care in the current study appears surprising, counterintuitive, and not consistent with the previously published research findings. The stresses of caregiving, expressed as effort and time invested in providing care, have been shown to have direct negative effects on satisfaction with life (Dahlrup, Ekström, Nordell, & Elmståhl, 2015; Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Meyers & Gray, 2000). Similarly, diminishing patient cognitive and physical functioning is distressing to family members, and exerts similar negative effect on caregiver mental health in general, and life satisfaction in particular (Kaufman, Kosberg, Leeper, & Tan, 2010; Papastavrou et al., 2014; Smith et al., 2011). Moreover, anxiety and satisfaction with life are also thought to have a significant inverse relationship (Lee et al., 2011), which was similarly absent in the present study.

The fact that these significant associations were not replicated in the current study indicates that the relationships between these constructs is likely influenced by other factors, such as subjective appraisal, coping skills, or social and family support (Contador et al., 2012; Pinquart & Sorensen, 2006) which were outside the scope of the first objective of the current study. Subsequent sections of the results and discussion section will consider more in-depth the complex relationship between care provision variables, mental health functioning, and possible influences of family dynamics.

4.2 Family Dynamics and Mental Health

The next objective of the study was to expand on the previous body of scientific work conducted primarily in Western countries, which documented the relationship between single indices of caregiver mental health and family functioning. The approach taken in the present study used canonical correlation analysis to uncover the pattern of family dynamics of dementia caregivers in Latin America which most strongly reciprocally impacts on their indices of mental health functioning, and to estimate the size of the relationship between them. It was hypothesized that healthy family dynamics would be significantly related with better caregiver mental health.

The results of the CCA provided strong support for the hypothesis, as the canonical correlation between these two constructs reached a large-sized effect. The family dynamic variables with the largest standardized canonical coefficients were family communication and empathy, followed by an index of overall family functioning. Among indices of mental health functioning, depression, satisfaction with life, and anxiety were revealed as having the largest standardized canonical coefficients. Subsequent hierarchical multiple regressions further identified the specific relationship between various family dynamics variables and caregiver mental health.

A more fine-grained analysis which took into account caregiver sociodemographic and care provision variables uncovered a significant inverse relationship between family cohesion and depression, which was also significantly related to worse overall family functioning as well as patient cognitive status. Caregivers were more likely to report more depression if patient's cognition was more declined, and if their family was more dysfunctional and less cohesive. Greater anxious symptomatology was related to worse

overall family functioning and more hours of care provision per week. Higher empathy in the family unit predicted greater caregiver satisfaction with life. Among caregiver variables, fewer months providing care were also predictive of greater satisfaction with life. Finally, lower caregiver cognitive functioning was revealed as the only significant predictor of caregiver burden, which emerged as not independently associated with family functioning variables.

This pattern of findings suggests that caregivers with higher levels of family empathy and better communication, as well as overall healthier family functioning, may experience higher satisfaction with life and less depression and anxiety. In the context of previously published research, the obtained findings are consistent with the reports of higher satisfaction with life and better psychological well-being (i.e., lower depression and anxiety) in caregivers who report healthy family functioning and strong communication (Caron, Boss, & Mortimer, 1999; Savundranayagam & Orange, 2011; Torossian & Ruffins, 1999). Having strong communication skills is associated with overall better family functioning (Olson, 2010), and may enable members to more clearly express their needs, feelings, and thoughts. Healthy levels of family functioning, reinforced with strong empathic communication patterns, may allow caregivers to feel more supported in their daily tasks of providing care to a family member with dementia. Caregivers who feel supported by the family members tend to appraise their situation in more positive terms and derive more perceived subjective benefits and satisfaction from providing care, and enjoy better mental health (Haley et al., 2003). High family cohesion has been associated with reduced caregiver depression in previous research (Torossian & Ruffins, 1999). The inverse connection between cohesion, or emotional bonding between family members, within the

family unit and caregiver depression is consistent with the Circumplex model, which predicts that family with healthy levels of unity are better equipped to deal with changing situations and stress (Olson, 2010).

The connection between cognitive decline in patients with dementia and caregiver burden has also been reported in the literature (Cohen, Colantonio, & Vernich, 2002; Gonzalez-Salvador et al., 1999). Arango-Lasprilla and colleagues (2009) found that caregiver-reported cognitive, but not physical, problems in the patient were significantly related to caregiver burden and depression in a sample from Latin America. Certain other studies, however, failed to find an association between worse patient cognition and higher caregiver depression or burden (Annerstedt et al., 2000; Zarit et al., 1980). A study conducted with family dementia caregivers from Colombia reported that, like in the current study, caregiver burden was not independently associated with family functioning variables, but was instead predicted by caregiver relationship status (Sutter et al., 2014). In the present sample, however, there was a significant unique impact of patient cognitive functioning, represented by their MMSE score, on caregiver burden. Since the Sutter et al. study did not include patient cognition as a control variable, and the present study did not control for caregiver relationship status in the analyses, it is difficult to draw firm conclusion as to the nature of the difference in the reported findings. Nonetheless, the results of the current study underscore the importance of patient cognitive problems, which appear to play a larger role than the family functioning variables, on caregiver experience of burden.

4.3 Family Dynamics and Quality of Care

There is a dearth of research highlighting the importance of family dynamics on quality of care, much less how this extends to Latin American dementia caregivers. Given the unique characteristics of this population, the next aim of the current study was to investigate the role of family dynamics in the quality of informal care provided by dementia caregivers. It was hypothesized that healthier family dynamics would be predictive of high quality of informal care by dementia caregivers.

Examination of bivariate correlations indicated that nearly all family dynamics were significantly associated with quality of care provision variables, such that caregivers provided better quality of care when their family dynamics were more healthy. In a series of hierarchical multiple regressions, family dynamics were significantly associated with quality of care provision after controlling for caregiver characteristics. Thus, both hypotheses of the third study objective were strongly supported.

Within regression models, provision of exemplary care was uniquely associated with family dynamic variables of empathy and general functioning, such that greater levels of empathic response and lower levels of dysfunction/pathology in the family unit were associated with higher quality of care. Additionally, fewer months spent caregiving were uniquely associated with higher quality of care. In the first regression equation including caregiver demographics and characteristics and the 6 family dynamics as independent variables and quality of care—Provide as the criterion variable, months spent providing care, empathy, and general functioning were all uniquely associated with quality of care after controlling for caregiver characteristics. Prior research indicates that longer time spent providing care to a loved one with dementia is related to declining caregiver mental and

physical health, which impacts the quality of care provided by informal family CGs (Smith et al., 2011). Similarly, caregivers are more likely to experience strain when more time is spent providing care (i.e., the ''wear and tear'' hypothesis) (Annerstedt et al., 2000; Haley et al., 1996; Townsend et al., 1989; Zarit, Todd, & Zarit, 1986), as well as when there is greater family dysfunction (Heru, Ryan, & Iqbal, 2004; Tremont, Davis, & Bishop, 2006). When caregivers are burdened, they may be less likely to form or sustain a meaningful relationship with the care recipient, and subsequently be less likely to provide exemplary care (Dooley et al., 2007). In contrast, caregivers generally report greater well-being when their families engage in greater empathic response (Sutter et al., 2014). Caregivers with healthier family dynamics, including greater empathy and family functioning, have been associated with greater help to the patient (Lieberman & Fisher, 1999), which in turn may yield provision of exemplary care.

Similar to the first, the second regression model including family dynamics and caregiver demographics and characteristics as the predictor variables and quality of care—Respect as the outcome variable, general functioning and empathy showed a unique association with quality of care—Respect, after controlling for caregiver characteristics and demographics. Research has shown that caregivers who experience family conflict are less likely to receive social and emotional support (Zarit, Todd, & Zarit, 1986), which may exacerbate caregiver strain. High stress has been associated with incidence of potentially harmful behaviors through increased depression (Smith et al., 2011). PHBs have subsequently been negatively related to the Respect subscale (Dooley et al., 2007). On the other hand, Cheng and colleagues found that positive exchanges between caregivers and family members were associated with lower burden and overload (Cheng et al., 2013). It is

possible that when caregivers perceive their family dynamics as healthy and supportive, they are able to empathize with the care recipient and may be more likely to form or maintain a significant connection with the patient. This suggests that such meaningful relationships allow the caregivers to increasingly respect the care recipients' wishes and viewpoints, which may be especially important for caregivers in Latin America, where caring for an older adult is seen as a way of showing respect (Neary & Mahoney, 2005).

4.4 Theoretical Model Evaluation

The final objective of the study was to assess the complex interrelationship between dementia caregivers' background characteristics, patient cognitive functioning, caregiver mental health, and family dynamics, with provision of exemplary care as the ultimate outcome in the theorized model. Significant relationships were hypothesized which linked caregiver background variables and patient cognitive functioning to caregiver mental health and family functioning via burden; family dynamics was hypothesized to have a direct, as well as indirect effect via mental health, on the final outcome variables of provision of high quality care. The results obtained from the analysis of the theoretical model, which was conceived on the basis of the Stress Process Model of caregiver functioning (Pearlin et al., 1990) and grounded in structural family theory (Minuchin, 1974; Olson, 2010), using structural equation modeling approach provided support for the majority of hypothesized relationships, and yielded a number of important findings.

Overall, the wholesome analysis of the complex network of relationships between patient cognition, caregiver burden, mental health, family dynamics, and quality of care provision yielded strong support for the study hypotheses. Specifically, lower patient cognitive functioning was found to significantly impact upon caregiver perception of subjective burden, which in turn yielded negative consequences of their mental health and family functioning, as predicted. Further, healthier family functioning was found to strongly and positively associate with provision of high quality, person-centered care, both directly and indirectly by way of mediated relationship via mental health. Also notable here is the indirect effect of patient cognitive functioning on caregiver family and mental health

functioning via subjective perception of burden, which also partially mediated this relationship.

An interesting yet unexpected result in the context of the tested model was revealed by the lack of significant relationship between caregiver background variables of age, months spent providing care, and hours per week spent caregiving, which were thought to encapsulate chronicity of their caregiving role, and caregiver burden. Other researchers have reported the importance of contextual caregiver factors in their subjective experience of caregiving overload. Papastavrou et al. (2007) reported significant impact of gender on caregiver burden, with female caregivers reporting higher levels of overload. Others identified patient gender, caregiver age, education, ethnicity, and family income level as some of the important background variables which significantly impact on caregiver burden (Brodaty et al., 2014; Dunkin & Anderson-Hanley, 1998; Leggett et al., 2011; Sun et al., 2013). In the present study low patient cognitive functioning was the best predictor of caregiver burden both in the theoretical model and in the hierarchical multiple regression analyses. This is also consistent with previous research in the area, as negative effects of low patient cognition has been reported in multiple studies (Arango-Lasprilla et., 2009; Allegri et al., 2006; Mioshi et al., 2013; Pinquart & Sorensen, 2003). There are some conflicting studies as well, however, which failed to find significant contribution of patient clinical variables to caregiver burden, and instead attributed increased subjective overload to factors such as low social support or poor coping strategies (Contador et al., 2012; Zarit et al., 1980). The diverse range of findings in the literature can be attributed to differences in participant sample characteristics, constructs measured, instruments used, and statistical analyses employed, all of which significantly complicates the task of drawing direct

comparisons between studies. It is argued, however, that low scores on the measure of cognitive functioning employed in the current study may indicate not only declining cognitive capacity indicative of advanced stages of AD, but can also be strongly related to various other manifestations of the disorder. For example, neuropsychiatric disturbances and problem behaviors are more common with increasing cognitive impairment (Matsumoto et al., 2007; Sorensen & Conwell, 2011). Therefore, it is possible that the construct of patient cognitive functioning used in the current study exerts such significant influence on caregiver burden and other subsequent variables in the model because it may carry with it the weight and variance attributable to other important sequelae of decreasing cognitive status in AD. Future studies ought to employ a wider gamut of instruments to obtain a more comprehensive view of not only patient symptomatology, but also of background characteristics of the caregivers.

Another important result revealed by the model analysis was the presence of the Heywood error, or negative variance estimation, in one of the subscales of the measure of quality of care. The significance of this finding can be construed that exemplary care provided by family dementia caregivers in the current sample recruited in Latin America is not captured along the two overlapping but separate constructs of provision of personalized care and respect, as has been found in the Western sample where the instrument was originally created and validated (Dooley et al., 2007). This distinction is arguably attributed to cultural differences between the North American sample of dementia caregivers and the participants of the current study. Instead, high quality family-based care provided to a family member with dementia by Latin American caregivers is likely to be both respectful and personalized, and indistinguishable psychometrically into two parallel sub-constructs.

Important differences in the attitudes towards care provision have been noted between societies with individualistic orientation, such as those in many developed countries, and other cultures, such as those found in Southeast Asia and Latin America, which still place significant value on familial ties and intergenerational interdependence (Chee & Levkoff, 2001; Llanque & Enriquez, 2012). Caregivers from developed countries command higher standard of living, and greater access to nursing and long-term care facilities, which, in addition to the lack of societally imposed expectations of providing care for the loved one with dementia makes them significantly more likely to pursue institutionalization of their family member (Mausbach et al., 2004). In the context of Latin America, however, besides fewer options for continued health care, there exists a significant cultural variable of familismo, which dictates that provision of care to older family members is an expectation, a blessing, and a virtue (Koerner & Shirai, 2012; Losada et al., 2006). Qualitative analysis of interviews with a large sample of Latino caregivers of individuals with AD revealed a facilitating factor of familismo in provision of care to a relative, with caregivers reporting that they feel strongly about the importance of family caring for each other, and that they derived satisfaction form providing care (Gelman, 2014). The findings of the current study are solidly in line with this observation, as satisfaction with life consistently emerged as significantly associated with better indices of mental health and family functioning.

Caregivers, despite reporting feeling burdened, anxious, and depressed, manage to derive meaning and satisfaction in providing care to their elderly husband, wife, aunt, uncle, parent, or grandparent in a respectful, personalized way. Results derived from qualitative and quantitative studies of the underlying cultural and family processes in dementia caregiver population in Latin America may be used not only to inform the

development of interventions to improve their functioning, but perhaps also to implement and emulate their strong family values and high quality of family-based care in the developed countries.

4.5 Clinical Implications

The findings of the present study have a number of important clinical implications. One of the principal implications for clinical practice with dementia caregivers in Latin America suggests that in an effort to improve quality of care for dementia patients, future interventions should target empathy and overall family functioning as important family dynamics constructs. The results of the current project indicate that studies of interventions to improve quality of care place more emphasis on increasing empathic response by the caregiver, and on improving overall family functioning, which were both associated with provision of quality care and respect towards the care recipient. Prior intervention research has primarily focused on improving caregiver mental health by targeting family dynamics, such as improving family cohesion (Mitrani et al., 2006), communication (Tremont, Davis, & Bishop, 2006) and family conflict (Sutter et al., 2014). However, studies aimed at improving quality of care via enhancement of family dynamics remain scarce. The results of the present study suggest that family-based interventions for caregivers of individuals with dementia could impact the quality of patient care by improving general family functioning and levels of empathic responding within the family unit. These results shed a light on an understudied region where family relations play an important role in everyday life, especially for individuals affected by chronic and neurological conditions and their caregivers (Annerstedt et al., 2000; Mausbach et al., 2004; Losada et al., 2006). Previous studies have revealed the protective nature of family relationships in the cultural context, with Latino informal caregivers reporting lower levels of burden and depression as a function of familism values, when compared to caregivers from other cultures (Koerner & Shirai, 2012). Latino familism has been identified as a factor in delayed institutionalization

of dementia patients (Tune, Lucas-Blaustein, & Rovner, 1988), and Latino caregivers with stronger identification and attachment to their families were most sensitive to family disagreement and experienced greater physical and depressive symptoms, as well as higher levels of burden (Zarit et al., 1998). Future interventions could highlight the importance of improved empathic response and healthier family functioning in an effort to improve patient quality of care.

Possible strategies for such interventions could include a particular focus on skills such as perspective taking, efforts to interpret the psychological states underlying the care recipient's verbal and nonverbal communication, responding sensitively to the patient, and expressing caring and understanding in a nonjudgmental, accepting, and emotionally validating manner. The ability to respond empathically during times of stress may serve to create and maintain satisfying and meaningful relationships (Sorensen et al., 2002), resulting in better quality of care provision. Additionally, prior research has shown that providing informal caregivers with respite programs and access to adult day care services for their family members with dementia increases caregiver well-being and reduces levels of anger, stress, and depression (Lieberman & Fisher, 1999; Scharlach, Li, & Dalvi, 2006). Better caregiver mental health functioning in turn has been related to higher likelihood of providing exemplary care (Dooley et al., 2007). This could prove essential and beneficial for caregivers who have been providing care for extended periods of time in order to improve their quality of care provision, since the findings of the present study indicated that longer duration of providing care was associated with reduced quality of care provision. Therefore, creation and implementation of services such as respite programs (which are generally scarce in Latin America) (Lehan et al., 2012) could be beneficial for caregivers in this region when it comes to providing high quality informal care.

Additionally, quality of care provision was also impacted by caregiver mental health functioning, and, indirectly, by their subjective perception of burden as a function of care recipient's cognitive status. A significant negative relationship between the dementia patient's cognitive status and caregiver burden is an important discovery. It signifies that providing care to a person with dementia with increasingly reduced cognitive capacity creates more subjective feelings of burden for the caregiver, which may create a chain reaction of negative outcomes downstream. As the cognitive status diminishes, the patient loses capacity to perform more complex tasks, eventually requiring assistance with increasingly simple activities such as feeding and toileting. This indicates the need for more thorough clinical attention and development of support services and interventions for caregivers whose care recipients are increasingly frail and exhibit lower cognitive functioning, which in turn likely places greater demand on the caregiver to provide assistance with a wider range of everyday activities, which, according to the results of the current study, may result in a negative cascade of consequences which may impact the quality of care provision. Equally important is clinical attention and rehabilitation strategies for the dementia patient. Recent advances in the development of empirically-supported interventions which combine cognitive rehabilitation, stimulation, and physical activity can benefit individuals with dementia and their caregivers (Clare et al., 2010; Woods et al., 2012; Wu & Koo, 2015). Though more research is needed in the area, the results of the current study suggest a possibility to affect caregiver quality of care provision indirectly by addressing their care recipient's cognitive decline.

The caregivers reported providing care for many hours per day, and experiencing high indices of burden. Nevertheless, most caregivers reported experiencing satisfaction with life. Possible influence of familismo and other positive characteristics of Latin

American culture may serve as a buffering and protective factor in caregiver mental health functioning. It is probable that though caregivers find their caregiving duties difficult, they also derive meaning and satisfaction from providing them, a potentially important entry point for therapeutic support and interventions grounded in positive psychology. On the other hand, Gelman (2014) warned of the need to recognize diversity among the needs and experiences of this diverse group of caregivers, as well as the range of culture-driven attitudes towards their caregiving role. It is likely that while some families are completely willing and capable of caring for their old and sick members, others do so at a great cost to themselves and ultimately the care recipient. Development of services which incorporate a complex role that familismo plays in the life and outlook of Latin American caregivers is of importance. For maximum effectiveness, such services ideally must be tailored to the individuals and particular needs of each family (Brodaty, Green, & Koschera, 2003). Depending on the circumstances, this could involve providing culturally-informed counseling to help a family member acknowledge, without feelings of guilt or shame, their reluctance to assume the caregiver role, in light of their belief that their relatives, neighbors, and community expect them to do so (but if their family, financial, personal, or other factors preclude them from doing so). The frequently-held cultural belief that the best care is provided by a family member must be evaluated against objective factors, such as advanced cognitive and physical decline of the patient or other medical necessity, which may make family-based care provision inordinately costly for the caregiver and the family unit. In such circumstances psychologists may be urged to provide culturally sensitive therapeutic support to caregivers who are disinclined to admit their frail family member in advancing stages of dementia to a long-term care facility.

Prior research showed the importance of appraisal and coping in improving various aspects of functioning mental health functioning (Kim et al., 2012), and to date there have been very few clinical intervention studies with dementia caregivers in Latin America. One of the first of such interventions employed a therapeutic group-based program grounded in cognitive-behavioral theory with a sample of dementia caregivers in Colombia. This intervention proved a resounding success among the participants, and produced a significant reduction of depression and burden, and increase in satisfaction with life which maintained up to three months post-treatment (Arango-Lasprilla et al., 2014). Perhaps more importantly, anecdotal reports from the caregivers indicated that the program fostered a sense of community among the participants, who continued their informal meetings to provide support to each other, share experiences, and enjoy each other's company long after the program concluded. Though individualized treatment approaches have generally been shown to be more efficacious than group-based modalities, it appears that in Latin America such group treatments provide other important therapeutic support to the caregivers (such as increased sense of belonging and socialization), which may go undetected by researcher-selected instruments. A combination of CBT-based approaches together with exercises aimed at improving family functioning and communication skills, such as empathic listening and responding, in a group setting could prove to be even more efficacious in improving mental health and family functioning outcomes.

4.6 Limitations and Future Directions

Despite the current study showing strong support for targeting empathy and general functioning as unique family dynamics in dementia caregivers in Latin America, along with other important findings, it has several limitations, which in turn provide directions for future research. The cross-sectional nature of the study impedes causal inferences to be drawn between caregiver family dynamics and mental health, and provision of exemplary care. Though such relationship was hypothesized and received strong support by the results, healthy family functioning may provide support to the caregiver and in turn result in provision of exemplary care. It may also be possible that caregivers who are providing high quality of care may cope with caregiving stress more effectively and subsequently may experience better mental health and engage in healthier family dynamics. As a result, future studies should collect longitudinal data on these constructs in an effort to infer causal relationships between patient cognitive functioning, which is expected to decline with the passage of time, and caregiver mental health, family dynamics, and quality of care, all of which will likely be impacted by the changing circumstances.

A number of conceptual limitations are related to measurement and instrumentation. Patient cognitive functioning was indicated by only one measure (the MMSE score). A more complete outlook on patient functioning can be provided by including the results of a comprehensive neuropsychological battery, as well as indication of presence of neuropsychiatric symptoms. Other important patient variables could include likelihood of early-onset AD, time since diagnosis, and pharmacological factors (e.g., anticholinergic, psychotropic, anxiolytic medication regimen, etc.). Potentially important caregiver valuables to be included in future research are indices of physical health, more detailed

information on financial resources, relationship to the patient, and the quality of the relationship with the care recipient prior to the diagnosis.

The construct of mental health included measures of depression, anxiety, burden, and satisfaction with life. It could be that other aspects of mental health not measured in the present study (e.g., anger, hostility, resilience, optimism, etc.) also play a role in caregiver functioning. In the context of the Stress Process Model, inclusion of other variables related to coping styles and strategies, attitude towards familismo and the role of extended family may have been important. This limitation is applicable to the construct of family dynamics. While the measures which were employed provided a valuable insight into caregiver family functioning, an assessment device such as the Structural Family Systems Rating-Dementia Caregiver (SFSR-DC), a process-oriented, multidimensional, and observational instrument, could potentially be even more informative and illuminating in uncovering the underlying processes of family interactions which are most important for caregiver mental health functioning and the spectrum of quality of care provision.

The concept of quality of care in the present study was measured from the point of view of high-quality, person-centered exemplary care provision. Future research design on care provision could include measures of other components of quality of care, such as those addressing instances of inadequate or negative care (e.g., Potentially Harmful Behavior Scale, Frustrations of Caregiving Scale, Dementia Management Strategies Scale, etc.). Quality of care provision was assessed using a self-reported caregiver measure, and did not take into consideration care recipients' perception of the care they received. A dyadic-consensus approach, inclusion of multiple individuals within the family system, as well as use of observational or objective measures of quality of care provision would make a valuable contribution to the scientific literature on the topic. The instruments were self-

administered, which does not preclude presence of bias in responses related to social desirability or symptom exaggeration.

Inclusion of other important variables would likely help improve the tested theoretical model. However, the desire for greater precision in measurement had to be balanced with the practical aspect of carrying out the research study. The participants kindly donated their valuable time, up to an hour and a half, in order to complete the research measures. Some of the caregivers who took part in the study, upon concluding their participation, had to return together with their family member with dementia to their home in the coastal city of Veracruz by bus—a five hour long journey from Mexico City, located in the center of the country. While potentially useful, the inclusion of more research instruments would place an undue burden on the study participants and potentially require them to spend even more time answering the questionnaires, or result in incomplete datasets because some participants may refuse to answer any more questions, given their already significant investment of time. The sample size for the current study was anticipated to be larger, which would have allowed for more robust testing of the hypothesized model.

Next, the instruments employed in the study were translated, adapted, and validated in the Spanish-speaking populations. However, since they were not developed in the context of particular cultural nuances of Latin America, they may not fully capture the multidimensional nature of the caregiver experience. For example, even though it was not used in the present study, ISEL-12, a measure of perceived social support, has been translated and validated for use in Spanish-Speaking Latino populations (Merz et al., 2014). However, some of the items on the scale, such as "If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me" reflect a

Western-centric focus of the choice of activities (i.e., go to a movie) and what is important in regards to social support. On a related note, in regards to measuring the underlying constructs, the present study employed a Likert-style scoring procedure for the Zarit Burden Inventory which ranged from 0-4, which produces total scores from 0-88. In many Spanish-speaking countries, however, the ZBI is scored using a Likert scale of 1-5, which produces responses ranging from 22 to 110 (e.g., Maseda et al., Pardo et al., 2014). This discrepancy complicates cross-study comparison of average scores and classification of the caregiver experience of burden. While the findings obtained in the present study are novel, important, and actionable, the development and validation of measurement tools in the cultural environment of Latin America (or many other global regions) will have a positive impact on measurement precision and subsequent applicability and implementation of the results.

All caregivers were recruited from major neuroscience institutes in Argentina and Mexico where patients received support for their disease, which is a precious and scarce resource in the region. While some participants had to travel from other parts of the country in order to attend a scheduled appointment with a neurologist, the majority came from the surrounding metropolitan areas. The experience of caregivers who live in remote, rural areas, as well as in other countries of Latin America (e.g., Guatemala, Honduras, Peru, etc.) with limited access to health care resources could be different, which has implications for generalizability of the study findings. The sample of caregivers of Mexico was small, and the results are possibly specific to the individuals who participated in the current study. An important future like of work will include obtaining comparable large samples of caregivers from various countries in Latin America in order to compare their adjustment, functioning, and quality of care provision while controlling for standard of living and cultural variables.

Future studies must address the remaining gap in knowledge regarding the experience of family caregivers for individuals with dementia and other neurological conditions in this historically understudied and underserved global region.

4.7 Conclusion

The current study was among the first to apply the Stress Process Model in conjunction with concepts derived from structural family theory to create a multidimensional model of the interrelationship between patient cognitive status, dementia caregiver family and mental health functioning, and their ultimate impact on quality of care provision in Latin America. The study uncovered an important relationship between lower patient cognitive functioning and increased burden in caregivers, which in turn negatively impacted their family and mental health functioning. Healthy family dynamics were found to have a significant positive effect on provision of high quality person-centered care to the person with dementia, partially mediated by caregiver mental health.

Additionally, the findings highlight the importance of healthy family functioning in dementia caregivers' mental health, and the impact of family empathy and general functioning on the provision of exemplary family-based care to a person with dementia. In cultures where familism plays a significant role, especially when caring for a relative with dementia, a focus on relationship-oriented coping strategies may prove to benefit quality of care for persons with dementia. Interventions aimed at improving family relations in regions with collectivistic and family-oriented cultures like that in the present study may improve empathy and reduce family conflict, and consequently improve quality of care for individuals with dementia.

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